

Cancer Care and Your Rights

A guide for people with cancer, their families and friends



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

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First published November 2009 as *Understanding Your Rights* (NSW edition). This edition May 2023.

© Cancer Council Australia 2023. ISBN 978 0 6455233 6 2

Cancer Care and Your Rights is reviewed approximately every 3 years.

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

Editor: Nicole MacKee. Designer: Eleonora Pelosi. Printer: IVE Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative. We thank the reviewers of this booklet: Prof Sarah Lewis, Faculty of Medicine and Health, The University of Sydney, NSW; Kevin Bloom, Senior Social Worker, Haematology and Bone Marrow Transplant, Royal North Shore Hospital, NSW; Danielle Curnoe, Consumer; Alana Fitzgibbon, Clinical Nurse Consultant – Gastro-Intestinal Cancers, Cancer Services, Royal Hobart Hospital, TAS; Hall & Wilcox (law firm); Johanna Jordaan, Consumer; Dr Deme Karikios, Medical Oncologist, Nepean Cancer and Wellness Centre, Nepean Hospital, NSW; Melissa Lawrie, Breast Cancer Clinical Nurse, Cancer Services, Gold Coast Hospital and Health Service, QLD; Jacqueline Lesage, Consumer Reviewer, Cancer Voices NSW; McCabe Centre for Law and Cancer, VIC; Louise Pellerade, 13 11 20 Consultant, Cancer Council WA; Andrew Potter, Consumer; Siân Slade, PhD Candidate, Nossal Institute for Global Health and Non-Executive Director (health, disability sectors), VIC; Paula Watt, Clinical Psychologist, WOMEN Centre, WA. We would like to thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

Note to reader

Always consult your doctor about matters that affect your health, 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 – 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 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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



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About this booklet

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

Many people feel shocked and upset when told they have cancer. Understanding the health care system and what you can reasonably expect from your treatment team can help you work in partnership with your health care providers and take an active role in your care.

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

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

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



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



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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Tips



Key questions about your health care rights

Patients have certain rights and responsibilities when accessing health care in Australia. Knowing your health care rights and responsibilities – and understanding how you can play an active role in your health care – can help you get the best possible outcomes.

Q: What are health care rights?

A: The Australian Charter of Healthcare Rights¹ sets out 7 key rights for people receiving health care.

You have a right to access, safety, respect, partnership, information, privacy, and to give feedback (see pages 6–7 for more details). These rights apply to everyone receiving health care in Australia.

Q: Why are rights important?

A: Knowing your rights and what you can reasonably expect from your treatment team and health care services will help you to better understand the health system and take an active role in your care.

It's important that you feel comfortable to ask questions and get the support you need.

Health care that responds to your needs, preferences and values, as well as the needs of your family and carers, is known as person-centred care. This means that your health care providers will respect your care goals, and involve you as an equal partner

when planning your treatment and ongoing care. Working in partnership to make joint decisions about your care can lead to better outcomes.

Q: How are health care rights protected?

A: Everyone who works in a health service is responsible for upholding health care rights. This helps people receive safe, high-quality and person-centred care.

Some rights are legally protected. There are laws covering discrimination, medical treatment, the conduct of health professionals and hospital services, and the privacy of personal information. Health professionals and health care services must comply with these laws.

Other health care rights reflect fair and reasonable expectations for care. For example, you may want a second opinion if you're unsure about the treatment a doctor has recommended. It is 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, there is no law that says they have to. If your doctor is not helpful in seeking a second opinion, you can find one in other ways (see pages 32–33).

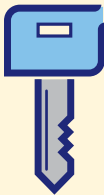
Q: Is discrimination unlawful?

A: In Australia, it is generally unlawful for health services to discriminate on the basis of age, disability, race, sex, intersex status, gender identity and sexual orientation.

Your health care rights

The Australian Charter of Healthcare Rights describes your rights when using health services. Below is a summary of the 7 rights included in the charter

Access



You have a right to access health services and treatments that meet your needs. If you have a current Medicare card and are treated in a public hospital as a public patient, you have a right to access care at little or no cost.

Safety



You have a right to receive high-quality, evidence-based care in an environment that is safe. If you are worried that something has been overlooked, talk with your health care provider and ask for a clinical review. This means that your condition and the treatment you are receiving is checked. If required, you should receive instructions about how to safely care for yourself at home.

Respect



You have a right to be treated as an individual, and with dignity and respect. You also have a right to have your culture, identity, beliefs and choices recognised and respected.

Partnership



You have a right to ask questions and make decisions about your treatment and care in partnership with your health care team. For example, you have the right to accept or refuse any treatment you are offered, and to decide whether to take part in clinical trials (see pages 35–36). You have the right to include family members and carers in your decision-making and meetings with doctors.

and how they may contribute to the quality of health care you receive. For more information, visit safetyandquality.gov.au/your-rights.

Information



You have a right to receive clear information about your health and the possible benefits and risks of different tests and treatments, so you can give informed consent. You have the right to receive information about the costs of tests and treatments and wait times. You can ask questions if you need more information. If English is not your first language, you can request interpreter services, which may be free. If something goes wrong, you should be told about it and what is being done to fix it. You have the right to obtain a second opinion and to gain access to your own health information.

Privacy



You have a right to privacy. Your personal and health information must be kept private, secure and confidential (except in limited circumstances). This includes discussions with health care providers, and your written and online medical records.

Give feedback



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

In addition to the Australian Charter of Healthcare Rights, The Private Patients' Hospital Charter sets out the rights and responsibilities of private patients in public and private hospitals and day procedure centres. Visit health.gov.au/resources/publications/private-patients-hospital-charter.

Q: What are patient responsibilities?

A: Health professionals understand that dealing with cancer is challenging and many people feel vulnerable at this time. Developing an open and trusting relationship with your health care team during this time is important. If you expect your health care providers to behave in a certain way – for example, to communicate openly – it helps to behave the same way in return. Many hospitals and treatment centres have guidelines on patient responsibilities that cover the following 3 areas.

Being considerate

These responsibilities relate to practical issues, including:

- treating staff and other patients with courtesy and respect
- being on time for appointments or letting the health care provider know if you are unable to attend an appointment
- following any policies of your health service, such as visiting hours, using mobile phones, smoke-free areas, etc.
- seeking permission if you would like to record consultations.

Being honest and open

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

Tell your health care team if:

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

- you're seeing more than one doctor or another health professional (including complementary or alternative therapy practitioners) for any part of your care
- you decide not to follow their advice – for example, by not taking the prescribed medicine or having certain tests
- you are taking any other medicines (including over-the-counter drugs, complementary and alternative medicines, and bush medicines). Some medicines interact with cancer drugs, and this can cause side effects or reduce a treatment's effectiveness.

Being flexible

Your doctor recommends treatment based on your initial test results and your overall health. Depending on how you respond to treatment, your doctor may have to adjust the agreed treatment plan. It's important to be flexible and understand that your treatment may change over time. If changes occur, you still have the right to be involved as an equal partner when deciding on a new treatment plan.

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



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested, may prevent successful treatment of the cancer and can be harmful. Cancer Council does not recommend the use of alternative therapies as cancer treatment.

How does the Australian health care system work?

Understanding how the health system works can help you find care that works best for you. For more about navigating the health care system, see the next chapter.

Public hospitals



- Funded by governments.
- If you are admitted as a public patient, medical care is free (although there may be a cost for some medicines).
- Often have a wider range of services than private hospitals.
- May also have some private services, such as imaging and pathology.
- You will not be able to choose your doctor and there may be a wait for some services.
- If admitted as a private patient, some costs may be covered by your private health insurance, but there are likely to be out-of-pocket costs.
- ▶ See pages 12 and 14.

Private hospitals



- Run by private organisations.
- Treatment may be partly covered by Medicare and private health insurance.
- You will have to pay part of the cost for medical services (gap payment).
- May be additional costs for accommodation, operating theatres and medicines.
- You will be able to choose your doctor.
- Waiting times for some health services may be shorter than in a public hospital.
- ▶ See pages 14–15.

Non-hospital care



- Mostly private, though some public services.
- If you visit a doctor outside a hospital, Medicare will pay 100% of the schedule fee for general practitioner (GP) visits and 85% for specialist visits, and approved imaging scans and blood tests.
- Many health providers charge more than the schedule fee and you will have to pay the difference. Ask how much you will have to pay when making an appointment.
- Private health insurance does not cover out-of-hospital medical service costs, which are covered by Medicare.

Medicare



- Funded by Australian taxpayers.
- Covers the cost of treatment in public hospitals, and partly covers doctors' fees for some services in private hospitals.
- Helps to cover part of the cost of visits to GPs and specialists.
- Once you have spent a certain amount on medical services, your benefits may increase (Medicare Safety Nets).
- Sometimes, health professionals accept the Medicare benefit as full payment for a service (bulk-billing).
- ▶ See pages 16–17.

Private health insurance



- You may choose to pay for private health insurance.
- If you have hospital cover, it will cover part of the cost of your care as a private patient.
- You will usually also have costs you have to pay yourself.
- If you have extras cover, it may help with the cost of allied health care such as physiotherapy.
- ▶ See page 17.

Gap payments



- Medical costs are often higher than the amounts covered by Medicare and private health insurance.
- The difference between these amounts is called a gap payment or out-of-pocket cost and you will have to pay this. Check with your health care team what your gap payments will be.
- ▶ See pages 14–15.

PBS



- Funded by the Australian Government, the Pharmaceutical Benefits Scheme (PBS) covers part of the cost of medicines.
- Once you have spent a certain amount of money on medicines, your medicines are free or the cost is further reduced (the PBS Safety Net).
- ▶ See page 20.

Navigating the health care system

Health care systems are complex and sometimes challenging to understand, particularly when you are dealing with the physical, emotional and financial impacts of cancer.

Australia's health system has 2 parts: the public health system and the private health system. People can be treated publicly or choose to use their private health insurance to be treated privately. Most people treated for cancer use a mix of public and private services.

Public health care

The Australian Government provides free or subsidised medical care and hospital services through Medicare (see pages 16–17). This is known as a “universal health care system”. If you have a current Medicare number, you have the right to receive free treatment as a public patient in a public hospital (even if you have private health insurance).

Public hospitals often provide a wider range of services than private hospitals, including:

- emergency departments
- specialist surgical and medical units
- allied health services.



For an overview of what to expect during all stages of your cancer care, visit cancer.org.au/cancercareguides. These short guides give an overview of recommended approaches to diagnosis and treatment for a range of different cancer types.

The cost of cancer

General practitioner (GP) – When you first notice the signs and symptoms of cancer, the first health professional you are likely to see is your GP. Your GP will arrange initial tests and scans and, if cancer is suspected, will refer you to a specialist for further tests.

GP consultations are subsidised by Medicare (see pages 16–17). Private health insurance (see page 17) does not cover GP consultations.

Diagnostic tests and scans – To confirm a cancer diagnosis, you may have a range of tests and imaging scans. These tests may be done in a public or private hospital or health service.

Medicare will cover some or all of the cost of tests and scans. Check with your health care provider what you may have to pay for these tests (out-of-pocket costs).

Treatment – Cancer treatments may be offered in both public health services and private health services. It's very important to understand the costs that you may have to pay yourself (out-of-pocket costs) before

making treatment decisions. This is called informed financial consent (see page 18). You may be able to have some of your treatments in the public system and some in the private system.

Keep in mind that there may be a period of waiting if you choose to switch from private to public care.

Follow-up care – After completing your treatment, your continuing care may be organised by your GP or your cancer specialist. Medicare may cover the cost of some or all of your medical follow-up services. You may also need to see allied health professionals, such as exercise physiologists and dietitians.

Some of these services may be covered by Medicare; talk to your GP to see if you are eligible for a Chronic Disease Management Plan.

If you have private health insurance for extras, you may be able to claim for part of the cost of some allied health services.

If you are being treated as a public patient in a public hospital:

- you can't choose your doctor or any other member of your health care team at the hospital
- you might have to wait longer for treatment than a private patient.

Cancer care delivered publicly includes:

- consultations with your oncologist or surgeon
- cancer treatments (e.g. surgery, chemotherapy, radiation therapy)
- tests such as blood tests, x-rays and imaging scans
- some allied health services (usually in outpatient clinics).

It's important to remember that both public and private patients have the same access to public hospital services.

Private health care

Some people prefer to be treated as a private patient so they can choose their own doctor, and may not have to wait as long for treatment. You can be treated as a private patient in both public and private hospitals and health services. The cancer care services listed above are also offered in the private sector.

Fees – Doctors, service providers and hospitals in the private sector can set their own fees. Some people pay for private health insurance to help cover the extra cost of treatment as a private patient in hospital. If a health service provided in a private hospital is on the Medicare Benefits Schedule (see page 16), Medicare covers 75% of the schedule fee for some services and private health insurance may cover at least 25%. Many doctors charge more than the schedule fee. Your health insurer may cover some or all of this cost; you will have to pay any costs not covered (gap payment). For details about Medicare benefits for GP visits, see page 16.

You will also be charged for hospital accommodation, operating theatre fees and medicines. Private health insurance may cover some or all of these costs, depending on your policy.

Discuss costs – Before being admitted to hospital as a private patient, it's helpful to ask:

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

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

Public hospitals – If you choose to be treated as a private patient in a public hospital, it is usually arranged on admission. However, if you have been admitted to hospital through the emergency department, an administration officer may come to your bedside to ask if you want to be treated as a private or a public patient.

You don't have to decide straightaway. You may like to first talk to your health fund or a patient liaison officer at the hospital.



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

What is Medicare?

The Australian Government provides free or subsidised medical and hospital services through Medicare to Australian citizens and permanent residents, and people who meet certain requirements (e.g. visitors from some other countries). The government sets fees for the medical services it subsidises, which are listed on the Medicare Benefits Schedule (MBS). The fees are known as schedule fees and the Medicare benefit for out-of-hospital services is usually 85–100% of that schedule fee.

Bulk-billing – Some GPs and specialists accept the Medicare benefit as full payment for a service, and you will not have to pay anything. This is called bulk-billing. Many doctors do not bulk-bill, so you will have to pay the difference between the Medicare benefit and the consultation fee. You may be able to find doctors who bulk-bill their services, by visiting healthdirect.gov.au/australian-health-services.

Many doctors charge more than the schedule fee. The difference between the schedule fee and the doctor's fee is called a “gap payment”. Note that private health insurance does not help cover the gap fee for doctors' consultations in the community (only in hospitals). If a health service is not listed on the MBS, you will have to pay the whole fee.

What Medicare covers – It covers hospital care when admitted as a public patient to a public hospital, and visits to GPs, specialists and optometrists. Medicare may cover the cost of certain medical supplies (e.g. breast prostheses, stoma supplies). There are also programs to help with the cost of other services, such as visits to a psychologist or allied health professionals. Talk to your GP to see if you are eligible.

What Medicare doesn't cover – It doesn't cover ambulance services (funding and costs vary according to the state or territory in which you

live and may be covered by your private health insurance), dental care (with exceptions), private home nursing services, and other services.

Medicare Safety Nets

This program can help reduce how much you have to pay for some out-of-hospital services. Once your out-of-pocket costs add up to a certain amount (called the threshold) during a calendar year, Medicare will pay you a higher benefit for some services until the end of that year.

Individuals with no dependants do not need to register for Medicare Safety Nets as Medicare automatically keeps a total of your expenses. Couples and families, however, must register for Medicare Safety Nets, even if you are all listed on the same Medicare card. For details, call Medicare on 132 011 or visit servicesaustralia.gov.au.

Private health insurance

Some people choose to take out private health insurance to help cover their future health care expenses. The amount you pay (the premium) and the health services covered vary depending on the company and the type of policy you select.

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. It is likely that you will have some out-of-pocket costs.

You can get hospital cover as well as cover for extras such as dental, optical and physiotherapy treatments. After you take out a policy, there will usually be a waiting period before you can claim benefits. For a general list of what Medicare and private health insurance covers in Australia, visit privatehealth.gov.au/health_insurance/what_is_covered.

Informed financial consent

You have a right to know if you have to pay for treatment and medicines and, if so, what the costs will be (see page 13). Before treatment starts, your doctors and other health care providers must talk to you about the likely fees that you will have to pay (called out-of-pocket costs). This is called informed financial consent. You can ask for this information to be put in writing, so you can refer to it during your treatment.

There may be costs associated with your treatment that 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, as well as the fees for the surgical procedure.

In some instances, such as in the case of an emergency, it is not possible to give informed financial consent before medical care. In such cases, your consent should be obtained as soon as possible afterwards.

Exploring medical costs

Understanding all treatment costs may play a role in your decision to use public or private services. It may be helpful to visit the Australian Government's online tool Medical Costs Finder, which is a general guide to the typical fees, private health insurance contributions and out-of-pocket costs for medical services in your area. The Medical Costs Finder covers services provided in and out of hospital. For more information, visit medicalcostsfinder.health.gov.au.

Also see privatehealth.gov.au/health_insurance/what_is_covered for a general list of what Medicare and private health insurance cover. If you have private health insurance, you will need to contact your health fund to find out what costs are covered in your policy.



Ways to manage health care costs

- Ask your health care provider for a written quote outlining their fees. If you receive a much higher bill, show them the quote and ask why the bill is higher.
 - Ask your GP to refer you to a doctor in the public health system.
 - Consider switching to a doctor who charges lower fees (if you are a private patient).
 - Ask to be treated as a public patient in a public hospital, even if you have private health insurance.
 - Talk to your doctor about treatment options. Some newer treatments can be very expensive and may not offer greater benefits than traditional approaches. Ask your doctor if other treatments might be as effective but cost less.
 - Find out if you can pay in instalments or have more time to pay your bill. If your health care provider agrees, check if you will be charged interest.
 - Ask your doctor if they would consider reducing their fees if you can't afford treatment.
 - Ask your GP if they can give you a long-term referral to your specialist at the end of your treatment. This is known as an "indefinite referral". It may save you time and money if you require follow-up over several years (standard GP referrals are valid for 12 months and specialist referrals are valid for 3 months). Note, an indefinite referral is not valid for new or unrelated conditions, and it's important to visit your GP if you have any health concerns and for regular check-ups.
- For more information on the financial impacts of cancer, see pages 53–59 of this booklet and our *Cancer and Your Finances* booklet.

Medicines and the PBS

Many drugs used to treat cancer are expensive. The Pharmaceutical Benefits Scheme (PBS) covers all or part of the cost of many prescription medicines for people with a current Medicare card. Medicines that you buy from a pharmacy without a prescription (over-the-counter medicines) are generally not covered by the PBS.

Concession cards and allowances

Some PBS medicines are cheaper for people with a Pensioner Concession Card, Commonwealth Seniors Veteran Card, Health Care Card or Department of Veterans' Affairs Health Card. You will need to show your card to the pharmacist when you get your prescription filled. People who receive some Centrelink payments may be eligible for a Pharmaceutical Allowance, which can help to cover the costs of prescription medicines. For details, visit servicesaustralia.gov.au.

PBS Safety Net

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

Generic medicines

Your pharmacist may ask if you would like a generic brand of your prescribed medicine because it will be cheaper. Generic medicines contain the same active ingredients and meet the same high standards of quality, safety and effectiveness set by the Therapeutic Goods Administration, which regulates medicines sold in Australia. It is your choice whether to buy the generic or original brand.

Non-PBS prescriptions

Doctors may prescribe a medicine that is not on the PBS. This is called a private prescription. You will need to pay the full price for these medicines and it will not count towards the PBS Safety Net. If you have private health insurance, it may cover some or all of the cost of a private prescription. Check with your insurer.

You may also be able to access medicines that are not on the PBS by joining a clinical trial (see pages 35–36) or through a compassionate access scheme (see below).



Paying for medicines

- Public patients in public hospital do not pay for most drugs as the cost is covered by the PBS. Ask your treatment team if you have to contribute to the cost of your drugs (there may be a cost for some oral chemotherapy drugs).
- If you choose to be treated as a private patient, you may have to contribute to the cost of chemotherapy drugs. Check with your doctor and health fund before starting treatment.
- Some doctors only prescribe PBS medicines to make treatment affordable. Ask your doctor for every option – including private prescriptions – so you can make an informed decision about your treatment. You may also be able to get some drugs at a reduced cost on compassionate grounds (these are called compassionate access schemes). Ask your doctor if this might be an option for you.
- You usually have to pay for medicines you take at home. Keep a record of your PBS medicines on a Prescription Record Form, available online or from your pharmacist, so you know when you've reached the PBS Safety Net threshold.

Key points about navigating the health care system

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

Public health care and Medicare

- If you're a public patient, the public hospital system pays for your care and treatment in a public hospital.
 - Medicare also provides benefits for out-of-hospital services, such as doctor visits and imaging scans. These may be bulk-billed or you may have to pay the bill and then claim the Medicare benefit.
 - Once your expenses reach a certain amount (threshold), the Medicare Safety Net further subsidises out-of-hospital costs.
-

Private health care and financial consent

- You may choose to take out private health insurance to help cover certain medical and hospital expenses. Waiting periods may apply before you can claim benefits.
 - Private patients can choose their own doctor and may have a shorter wait for treatment.
 - If you are treated as a private patient in a public or private hospital, your health care providers should talk to you about how much your tests, treatments, medicines and hospital care will cost. This is called informed financial consent.
-

Paying for medicines

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

Your health care team

Doctors, nurses and other health professionals offer a range of services to assist you, your family and carers. When you notice signs or symptoms that might be cancer, or have a positive screening test, you will usually see a GP. Your GP will order initial tests and scans. If the results suggest that you might have cancer, you will be referred to a specialist doctor for further tests, diagnosis and staging.

Your specialist can answer questions about treatment and address any concerns you may have. However, there is often limited time during a specialist consultation. Other members of your treatment team (e.g. GP, cancer care coordinator or social worker) may be able to answer some of your questions more quickly than your specialist (for urgent matters, call 000). Your GP will also play an important role in supporting you throughout treatment, recovery and your ongoing health care. This is why it's important to develop a good relationship with a particular GP.

The table on the next 2 pages describes the roles of the most common members of the treatment team. Not all of these health professionals will be in the hospital or treatment centre, and they may have different titles depending on where you have treatment.



People living with advanced cancer may face additional issues to those discussed in this booklet. Cancer Council has free booklets about advanced cancer, palliative care and end-of-life issues, as well as fact sheets about getting your affairs in order, what happens to debts after death, and superannuation and cancer. For details, call 13 11 20 or visit your local Cancer Council website.

Health professionals who can help

GP or family doctor

- assists you with treatment decisions
- refers you to specialists as well as allied health professionals
- can help arrange second opinions
- works with your specialists in providing follow-up care after treatment finishes
- continues to see you for day-to-day health care issues
- gets to know you and your medical history
- may support you during telehealth appointments with specialists if you live in a rural area

Cancer specialist

- may be a medical oncologist, surgeon, radiation oncologist or haematologist
- depending on the type of cancer you have, you may need to see several specialists who will look after different aspects of your care
- diagnoses the cancer and supervises your treatment, follow-up and overall care
- can answer any questions you have about your treatment
- usually works as part of a multidisciplinary team (see page 27)
- if you are treated in hospital, junior medical staff, such as registrars and resident medical officers, may be able to help you with questions and concerns

Cancer care coordinator

- a senior specialist nurse who may be called a clinical nurse consultant or clinical nurse specialist
- coordinates your care throughout diagnosis and treatment, and works closely with specialists and other members of the health care team
- provides information and support
- in a larger hospital may coordinate care for specific cancer types, while in a smaller hospital there may be a general coordinator or none at all
- in rural areas, cancer care coordinators may attend with the visiting oncologist
- in hospitals that don't have a clinical nurse consultant or cancer care coordinator, the nursing unit manager may have a similar role
- in some cases, more than one nurse may be involved (e.g. a surgical nurse)

Social workers	Physical and occupational therapists	Other health professionals
<ul style="list-style-type: none"> • provide counselling, emotional support and advocacy at all stages of living with cancer • provide information and access to practical support services including accommodation, transport, financial support, child care and home care services • assess what sort of support you need, and identify ways you can receive this support • link you with the people and services best able to meet your needs 	<ul style="list-style-type: none"> • physiotherapists help you to move and exercise safely to regain strength, fitness and mobility • exercise physiologists prescribe exercise to help people with medical conditions improve their overall health, fitness, strength and energy levels • occupational therapists offer equipment/aids and advice about getting back to your daily activities • speech pathologists help with speech or swallowing issues after treatment 	<ul style="list-style-type: none"> • psychologists or counsellors help you understand and manage your emotional response to diagnosis and treatment • dietitians help with nutrition concerns and recommend changes to diet during treatment and recovery • radiographers perform x-rays, mammograms and other scans • radiation therapists plan and deliver radiation therapy • genetic counsellors provide advice for people with strong family histories of certain types of cancer • pharmacists dispense medicines and give advice about dose and side effects



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

Deciding on specialist care

It is important that you feel comfortable and confident with your choice of specialist because you will have a lot of contact with them and they will influence your care.

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

Choosing a specialist

You need a valid referral to claim Medicare benefits for a private specialist visit. This referral can come from a GP or another specialist.

You have the right to be treated as a public patient in any public hospital. If you are treated in the public system, you will be treated by the specialist appointed by the hospital, and you may see different specialists during the course of your treatment.

You might want to research public treatment centres that specialise in the type of cancer you have (see *Specialist treatment centres*, page 28). Keep in mind that if you choose to be treated in a public hospital outside your local area, you may have to wait longer for treatment. Talk to your doctor about the best option for you.

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

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

Key issues to consider

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

Number of patients – Some specialists have expertise in treating certain types of cancer because they see a large number of patients with that cancer. For some cancer types, there is evidence that specialists who treat a lot of patients with similar cancers have the best treatment outcomes.

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

The MDT often includes surgeons, medical oncologists, radiologists, radiation oncologists, pathologists, cancer care coordinators and nurses, as well as allied health professionals, such as a physiotherapist, genetic counsellor, dietitian and social worker (see pages 24–25). The team meets regularly to review cases, consider treatment options and discuss ways to help people cope with the physical and emotional effects of cancer.

Not all specialists are part of an MDT, but you may be able to check online. For example, Lung Foundation Australia has an directory of MDTs in Australia at lungfoundation.com.au. In NSW and the ACT, you can search to see which doctors are part of an MDT at canrefer.org.au.

Specialist treatment centres – These centres have multidisciplinary teams of health professionals experienced in treating particular cancers. Specialist treatment centres have many patients and also tend to treat rare cancers or cancers that don't have a typical response to treatment. They are often teaching centres, which means you might be treated by a junior doctor who is supervised by a specialist.

You may want to ask your GP or other doctors about centres that specialise in treating the type of cancer that you have. It's your right to be referred to a specialist in one of these centres, even if it's not in your local area.

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

Finding a specialist

Ask your GP – Your GP will be able to refer you to a suitable specialist or treatment centre. Your GP should have clear reasons for their choice. You are entitled to ask about those reasons and to receive a clear answer – for example, is it because the specialist has particular skills or simply because they are nearby?

You also have the right to ask your GP for a referral to more than one specialist (see *Getting a second opinion*, pages 32–33).

Search online – Check the websites of medical colleges for a list of specialists. For example, you can search for colorectal surgeons

on the Colorectal Surgical Society of Australia and New Zealand's website (cssanz.org). In NSW, you can search for cancer specialists on Canrefer (canrefer.org.au). You can also check a specialist's registration at the Australian Health Practitioner Regulation Agency (see page 50).

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.

Personal recommendation – If any of your relatives or friends have had a similar cancer, you may ask them about the specialists they saw.

If you live in a rural or remote area

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

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

If you are concerned about the waiting time in your local area, you can ask to be referred to a specialist or treatment centre in another area.

If you have to travel for treatment, you may be eligible for state and territory government programs that help cover your travel costs. For details, call Cancer Council 13 11 20 or talk to the hospital social worker.

It may also be possible to have some specialist consultations using telehealth.



Making treatment decisions

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

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

Understanding the type of cancer you have, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision.

You have the right to delay your decision until you feel you have had enough time to consider all your options. Check with your specialist how soon treatment should begin – it might not affect the success of the treatment to wait a while.

If you are confused or want to check anything, it is important to ask your specialist questions. It's often a good idea to have a family member or friend go with you to specialist appointments to join in the discussion, write notes, ask questions or simply listen. It may also be possible for them to join the consultation by phone or video call.



Decision-making steps

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

You may find it helpful to do some of the following:

- Weigh up the advantages and disadvantages of each treatment, and whether it will help you meet your treatment goals.
- Take a list of questions to the appointment and ask if you can record the consultation. For a list of suggested questions, see page 68.
- Ask if other treatments are an option (if only one type of treatment is recommended) or if there are any clinical trials that may be suitable for you.
- Consider how potential side effects might affect you, especially if they will have an impact on your lifestyle, sexuality, fertility, or ability to work; if you have a partner, it may help to discuss any side effects with them.
- Find out more about the treatment choices by: speaking to your specialist or cancer care coordinator; calling Cancer Council 13 11 20; getting a second opinion (see pages 32–33); contacting cancer support groups; and talking to family, friends or people who have had the same type of cancer.
- Share your concerns with your doctor or the treating hospital, if you're not happy with the information you are given or how it is given (for more about the importance of feedback and complaints, see the *Health care complaints* chapter on pages 45–52).
- Listen to our “Making Treatment Decisions” podcast in *The Thing About Cancer* series at cancercouncil.com.au/ podcasts.

Getting a second opinion

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

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

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

Reasons you may want to get a second opinion include:

- finding peace of mind
- ensuring you receive up-to-date advice and treatment
- getting a different point of view
- joining or finding out about a clinical trial (see pages 35–36)
- exploring and challenging advice from your first doctor
- not feeling at ease with your first doctor.

Finding another specialist

You can seek a second opinion by asking:

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



Seeking another opinion

- You have the right to ask for as many opinions as you need. You will need a valid referral from your GP or specialist to claim some money back on Medicare for these appointments.
- 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 may be able to help you find someone.
- Some specialists who have a heavy workload don't accept patients for a second opinion or may charge more.
- Second opinions can take time. It may take a while to be referred to the new specialist and to get an appointment with them.
- Once you find someone to give you a second opinion, your first specialist should share your test results with them.
- If you are a public patient, you may only be allowed to be on a waiting list to see a specialist at one hospital at a time. Your doctor may also not be able to refer you to another specialist in the same hospital.
- You can get a second opinion even if you have started treatment.
- You might decide to be treated by the first doctor or you may prefer to be treated by the second specialist.
- You may be able to get some financial support if you need to travel a certain distance to get a second opinion. All state and territory governments have travel assistance programs.
- If you are being treated in the public system, you can get a second opinion from a private specialist, but check first how much this will cost.

“I wasn’t happy with the treatment recommended by the first specialist my GP referred me to, so I asked for a second opinion.” VIVIEN

Treatment guidelines

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

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

All doctors should be familiar with treatment guidelines, regardless of where they work. Some treatment centres use their own guidelines. Specialists will tailor treatment to suit your situation – this treatment should still meet the recommended best practice guidelines. Ask your doctor what guidelines they are using – if there is not an Australian guideline, they may use international guidelines. Some patients find it helpful to read the treatment guidelines, and many guidelines are available online:

- Cancer Australia clinical practice guidelines (canceraustralia.gov.au/resources/clinical-practice-guidelines)
- Cancer Council Australia Clinical Practice Guidelines (cancer.org.au/clinical-guidelines)
- *Guides to Best Cancer Care* (cancer.org.au/cancercareguides)
- Optimal Care Pathways (cancer.org.au/health-professionals/optimal-cancer-care-pathways).

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Health professionals and researchers, including doctors, run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. People are recruited to test the new treatment (e.g. a drug, medical device, surgical method or test) to see whether it works and whether any side effects occur.

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

Joining a clinical trial

It is voluntary to join a clinical trial. You shouldn't feel pressured to take part or rushed into making any decisions that may affect your health or treatment. Take the time you need to decide whether to join - if you are unsure, you can ask for a second opinion from another specialist or talk to your GP. Call Cancer Council 13 11 20 for more information.

Before joining a trial, you need to give informed consent (see next page). This means you will be given written information about the key facts of the trial so that you can decide whether to take part.

You will be asked to confirm in writing (usually by signing a consent form) that you have read and understood the purpose, duration, required procedures, risks and possible outcomes of the research, and agree to take part in the trial. You will be asked to give consent again if the study changes or new information becomes available.

You can withdraw from a clinical trial at any time without giving a reason. If you do withdraw, you will still receive the standard treatment that is currently the best option for you.

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

Giving informed consent for treatment

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

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

This information is generally given in English. If you need an interpreter, call the Translating and Interpreting Service on 131 450.

Receiving and understanding this information before voluntarily agreeing to treatment is called informed consent. You will usually be asked to sign a document indicating that you understand the information you are given and agree to treatment. If you are confused or need more information, talk to your doctor.

Adults (people aged 18 and over) can give their informed consent – or refuse or withdraw consent – if they have capacity (ability to make decisions). This means you can understand and remember information about proposed choices; understand the outcomes of your decision; and communicate your decision. If you do not have capacity, another person may be able to make decisions for you (see page 39).

Consent is not needed in some instances, such as in a medical emergency or when the patient is unconscious or mentally incapacitated. If your medical team knows that you have recorded an advance care directive, they will take this into account. For information on advance care directives, see the next page.

Consent from children

As much as possible, children should be involved in decisions about their health care. They should be given age-appropriate information, be included in discussions about their treatment, and be encouraged to ask questions. It is important to ensure that the health care team considers your child's health care preferences.

As people under the age of 18 are legally considered minors, it's usually up to their parent or legal guardian to consent to health care (unless there are court orders in place that do not allow this). Generally, there is no set age at which a child or young person is able to consent to medical treatment under Australian common law. This means a minor may be able to independently consent to or refuse medical treatment if they fully understand the nature and possible results of the proposed treatment.

There are specific requirements in South Australia and Tasmania. In South Australia, a person over the age of 16 years may make their own decisions about medical treatment. In Tasmania, a child may be able to make their own health care decisions if a registered health practitioner is satisfied that the child meets certain requirements.



Talk to a lawyer if you need specific information about health care consent for children and young people in your state or territory.



Each state or territory has different laws about advance care planning and substitute decision-makers. Talk to a lawyer for advice specific to your situation. Cancer Council 13 11 20 may be able to connect you with a lawyer for help appointing a substitute decision-maker. You can also call Advance Care Planning Australia's advisory service on 1300 208 582, or visit advancecareplanning.org.au.

Advance care planning

Advance care planning involves thinking about your future health care and discussing your treatment goals and preferences for care with your family, friends and treatment team. This helps them to understand your goals, values and beliefs, and ensures that your wishes are respected if you lose the capacity to make your own decisions.

Advance care planning can be started at any stage, whether you are feeling well or ill. Everyone has their own preferences for medical care and these can change over time. As part of advance care planning, you may record your wishes in an advance care directive and appoint a substitute decision-maker.

Advance care directive

The written record of your health care wishes may be called an advance care directive, an advance care plan or a living will. This includes details of your values, life goals and treatment preferences for doctors, family members and carers to consider if you become unable to communicate or make decisions.

You may include details of treatments that you would have or refuse to have, as well as outcomes that you don't want and your preferences for end-of-life care. If your needs change, you can revise or cancel your advance care directive.

You can ask your doctor or hospital to place your advance care directive on your medical record. You can also save it online at myhealthrecord.gov.au (see page 42).

Substitute decision-maker

You can legally appoint someone to make decisions for you if at some point in the future you lose the capacity to make decisions yourself (see page 36). This can include decisions about your finances, property and medical care. A substitute decision-maker should be someone you trust who understands your values and your wishes for future care. Depending on where you live, the documents for appointing this person may be known as an enduring power of attorney, enduring power of guardianship or appointment of a medical treatment decision-maker.

Default decision-maker

If you lose capacity to give consent for medical treatment and you don't have an advance care directive or a substitute decision-maker, the law in each state and territory outlines who may make medical treatment decisions for you. This is usually someone close to you, such as your spouse or partner, family member or close friend. For more information, visit end-of-life.qut.edu.au.

Voluntary assisted dying

Voluntary assisted dying is when a person with an incurable condition or illness chooses to end their life with the assistance of a doctor or a health practitioner – using specially prescribed medicines from a doctor. This may be an option for

some people who meet all the strict conditions and follow certain steps required by laws in their state. Talk to your doctor to see if voluntary assisted dying is legal where you live.

► For more details, see our *Living with Advanced Cancer* booklet.

Key points about deciding on care

Your health care team

Throughout your cancer care, you will see a range of health professionals, from GPs, specialists and cancer care nurses to allied health professionals. Some will practise in hospitals and others in the community.

Information gathering

- It's your right to make decisions about your treatment. Being fully informed about all of your options will help you decide on your treatment plan.
 - Take the time you need to consider the advantages and disadvantages of each treatment option.
 - It can help to talk to more than one specialist to consider other treatment options or to get a different point of view (second opinion).
-

Informed consent

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

Advance care planning

- It is important to think about your future health care and discuss your wishes with your family, friends and treatment team. This is called advance care planning.
 - You can prepare an advance care directive to ensure your family and health care team know your treatment preferences.
 - You can appoint a substitute decision-maker in case you do not have the capacity to make decisions at some point in the future.
 - Voluntary assisted dying is available in some states. You will need to talk to your doctor to see if this is an option for you.
-



Protecting your health information

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

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 talk to a lawyer.

Medical records

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

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

Every health service you attend will keep a medical record about you, and they will add to that record each time you visit or have tests. If you have any concerns about the security of your health information, talk to your health service or ask to see a copy of their privacy policy.

My Health Record

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

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

Who owns my medical records?

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

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

Who can access my medical records?

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

Australian privacy standards establish a general rule that health care providers must give you access to the personal information they hold

about you when you request it. This includes your medical records. In some limited situations, the organisation has a legal right to refuse you access (see next page).

Giving people access to their medical records:

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

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

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

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

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



You can authorise someone else to see your medical records – such as a relative or guardian, interpreter or another health professional – by filling in and signing the required form.

If you make a complaint about your health care, your records may be provided to the health ombudsman or complaints commission in your state or territory. Your medical records may also be accessed by others if you make a claim for insurance benefits.

Why might access be denied?

In some rare situations, you won't be allowed to have a copy of your medical records, such as where another law requires your information to be kept private (e.g. if the information relates to legal proceedings), or if there's a serious risk that giving you access to the information could harm someone.

If your health care provider refuses to let you see your medical record, they must let you know the reasons.

How can I change my medical records?

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

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

If you disagree with the health service's decision, you can make a complaint to the Office of the Australian Information Commissioner (call 1300 363 992 or visit oaic.gov.au) or to the health ombudsman or complaints commission in your state or territory (for contact details, see page 49).



Health care complaints

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

Health services are also expected to acknowledge patient harm. Patients can expect to be told if something has gone wrong during their care, how it may affect them and what is being done to make care safe. Ask your health service if it has a policy about open disclosure.

Importance of feedback

The safety of the health care system requires the active participation of health professionals, patients and carers. Feedback helps to improve care by supporting what is being done well, highlighting what can be done better, and improving safety. You can provide feedback in several ways.

Compliments – Positive comments show health professionals that you value their service and standard of care.

Suggestions – General feedback allows minor problems to be dealt with to improve patients' treatment experience.

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

How to give feedback or complain

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

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

If you have a problem with a particular person, it is often best to talk to them face-to-face or on the phone. This may help to resolve the issue quickly. If you find it difficult to raise the issue directly, or your initial discussions were not satisfactory, you may prefer to send an email or write a letter. 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 have concerns about your health fund and have been unable to resolve these issues with the fund, the Commonwealth Ombudsman looks after private health insurance complaints and may be able to help (see ombudsman.gov.au).



If you feel unable to provide feedback or complain immediately, you can still raise your concerns at a later date. Keep in mind that organisations may not assess complaints after a certain amount of time has elapsed since the event, and there are strict time limits for medical negligence complaints (see page 51).

Steps for resolving a health care issue

- 1 Identify the problem and what you would like to happen to resolve it.
- 2 Talk to your specialist, a nurse or other health professional so they have the chance to resolve the issue immediately. A quick conversation may help to sort out a simple misunderstanding.
- 3 If your complaint is about a particular person and you don't want to talk to them directly – or you have spoken to them and the issue remains unresolved – speak to the cancer care coordinator, nursing unit manager or social worker at your hospital or treatment centre.
- 4 If you're not happy with the response from a health professional, or if you want to talk to someone neutral, contact the hospital's independent patient representative, complaints officer or patient advocate.
- 5 If you're not satisfied with the patient representative's investigation, contact the hospital's quality assurance department or the clinical governance unit of your public hospital. Smaller or private hospitals may not have a patient representative, but you can contact the nursing unit manager or general manager.
- 6 If you're still not happy with the outcome – or you don't want to raise the issue with the health care facility – contact your state or territory health complaints organisation (see page 49) or the Australian Health Practitioner Regulation Agency (see page 50). If you have a serious complaint that you want to take to a health complaints organisation, you may wish to obtain independent legal advice.

Making a formal health care complaint

To make a formal health care complaint, you need to contact your state or territory health complaints organisation (see table opposite). It can be helpful to check if there are any time limits or other conditions you have to meet before making a complaint.

Health care complaints should be in writing and can often be made by filling in an online form. If you are unable to make the complaint yourself, a relative, friend, guardian or health professional may be able to lodge the complaint on your behalf.

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

Once the case officer has completed their assessment, the relevant state or territory ombudsman or commissioner will write to tell you how they will deal with your complaint. They may decide to refer it for mediation or conciliation, which is an informal meeting to try to resolve problems.

Serious issues

Issues relating to public health and safety are referred elsewhere within the ombudsman's or commission's office for formal investigation. Serious cases against health practitioners may result in prosecution, and some cases may be referred to a registration board or another organisation for further consideration – see page 50 for information about the Australian Health Practitioner Regulation Agency and registration boards.

Health complaints organisations

ACT	ACT Human Rights Commission 02 6205 2222 hrc.act.gov.au/health
NSW	Health Care Complaints Commission 1800 043 159 hccc.nsw.gov.au
NT	Health and Community Services Complaints Commission 1800 004 474 hcsc.nt.gov.au
QLD	Office of the Health Ombudsman 133 646 oho.qld.gov.au
SA	Health and Community Services Complaints Commissioner 08 7117 9313 or 1800 232 007 hcsc.sa.gov.au
TAS	Health Complaints Commissioner Tasmania 1800 001 170 healthcomplaints.tas.gov.au
VIC	Health Complaints Commissioner 1300 582 113 hcc.vic.gov.au
WA	Health and Disability Services Complaints Office 08 6551 7600 or 1800 813 583 hadsco.wa.gov.au

Regulation of health professionals

Some health professionals are required to be registered and accredited; others are not.

Registered health professionals

The Australian Health Practitioner Regulation Agency (AHPRA) and 15 National Boards regulate the health practitioners listed below. Health practitioners must meet certain standards before they can be registered and accredited with a National Board. Registration helps ensure only trained and competent health professionals practise within these professions. Students in an approved study program or doing clinical training must also be registered with the relevant National Board.

AHPRA works with the National Boards to investigate complaints about health practitioners. If you have concerns about the health, performance or conduct of a registered health practitioner, you can notify AHPRA. It is unlawful for a person to pretend to be a registered health practitioner. You can check a health practitioner's registration at www.ahpra.gov.au.

Registered health practitioners

The following health professionals must be registered:

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

Unregistered health practitioners

Allied and complementary health practitioners who are not required to be registered with a National Board are known as unregistered health practitioners. They must follow the National Code of Conduct for health care workers, which sets minimum standards of conduct and practice. This code must be displayed in the premises. Unregistered health practitioners may also join a professional association that sets minimum standards of conduct and practice (further to those covered in the National Code). 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 a health complaints organisation (see page 49) or with their professional association (if they are a member).

Medical negligence

Health professionals have a duty to treat patients with reasonable care and skill. If you have been injured or suffered financial loss as a result of inadequate treatment or care, you may be able to make a claim for compensation (medical negligence claim). Inadequate treatment may include failure to diagnose or treat promptly, failure to advise you of risks of procedures, or giving you the wrong medicine. Medical negligence claims about cancer diagnoses and care are uncommon.

In most states and territories, the time limit for making a negligence complaint is generally 3 years from the date the injury occurred. Exceptions may apply where an injury was not discovered until later.

Proving negligence can be hard; you may have to go to court, and the process can be expensive. If you think you may have a case, it's important to get advice from a lawyer who specialises in medical negligence. To find a suitable lawyer, contact the Law Society in your state or territory.

Key points about patient feedback

Why give feedback

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

How to give feedback

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

Health professional registration

- Many health professionals are required to be registered and accredited by a National Board.
 - Unregistered health practitioners are not legally required to be registered with a National Board but must follow the National Code of Conduct for health care workers. They may choose to join a professional association.
-

Medical negligence

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

Insurance, financial and workplace issues

This chapter provides general information only about insurance, financial and workplace issues that may be relevant to people with cancer. For information specific to your situation, you should seek independent legal and financial advice.

► See our *Cancer, Work and You* and *Cancer and Your Finances* booklets.

Insurance

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

If you're not making a claim, you don't usually 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 what your insurance policy says about telling the insurer about health issues. When taking out a new policy, you generally need to provide your medical history, including cancer diagnosis. Insurance companies can refuse cover, but only on reasonable grounds. This does not include private health insurance; it is unlawful to be denied health insurance because of health issues, but there may be a waiting period before pre-existing conditions are covered.

Travel insurance

Getting travel insurance can be a major concern for people with cancer or who have had cancer, as cancer is generally considered a pre-existing medical condition. 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, or need to return home for treatment, or cancel your trip due to illness.

In general, you should be able to buy travel insurance for things that are not related to your cancer (like lost luggage, theft and cancelled flights). It may be difficult to buy travel insurance that covers cancer-related medical issues, but you should be able to get coverage for medical costs not related to cancer. If you have to tell them about any pre-existing health conditions, it's important to be honest – a claim may be denied if you withhold information.



How to get travel insurance

- Apply for a policy well before your departure date.
- Shop around – the terms and conditions may vary.
- Ask your specialist or GP to write a detailed letter outlining your condition.
- If you are travelling overseas, check whether there is a reciprocal health care agreement between Australia and the country you are visiting that covers some of the costs of medical treatment. For more information, visit servicesaustralia.gov.au and search for “reciprocal health care 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.

Financial issues

Cancer can affect your financial situation, but several options are available if you are in financial stress. You might talk to a social worker for support, who may suggest speaking to a financial counsellor to help you work out a plan to manage your finances. To find a counsellor in your area, call the National Debt Helpline on 1800 007 007 or visit ndh.org.au. Depending on where you live, Cancer Council may be able to provide financial counselling, call 13 11 20 for more information.

Dealing with debts

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

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

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

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

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

- ▶ For more information, see our *Dealing with debts* fact sheet and *Cancer and Your Finances* booklet.

Accessing superannuation

You may be eligible for a superannuation benefit on the basis of permanent or temporary incapacity or a terminal medical condition. Before you apply, it is important to get advice about how this will affect your retirement and whether there are any insurance policies attached to your superannuation account that you could claim on. You may also be able to access some superannuation early on the basis of severe financial hardship. Talk to your super fund, or call Cancer Council 13 11 20 to see if we can connect you with a financial adviser.

► See our *Superannuation and cancer* fact sheet.

Applying for government benefits

Services Australia (Centrelink) offers a range of payments that may be available to people with cancer, including the Mobility Allowance and the Disability Support Pension. You may also be eligible for the Pensioner Concession Card or the Health Care Card, which can help with expenses. Centrelink benefits may be income- and asset-tested or have other eligibility requirements. Medicare also has programs to help with the costs of certain medical supplies (e.g. breast prostheses, continence aids). For details, visit servicesaustralia.gov.au or talk to your social worker. If cancer or its treatment has caused permanent and significant disability, you may be eligible for support through the National Disability Insurance Scheme (NDIS). Call 1800 800 110 or visit ndis.gov.au.

Workplace issues

If you are employed or hope to return to work after treatment, you might wonder how cancer will affect your work life. It is up to you whether you tell your employer about your cancer, however, you may need to do so if your ability to do your job is affected or you need some changes to your work arrangements to help you continue your job or return to work.

You may be concerned about your leave entitlements, or about being discriminated against, changing your working hours, or being dismissed from your job. Some of these issues are dealt with differently depending on your industry and the state or territory you live in. You may need to get specific advice from a lawyer who specialises in employment matters.

Some people resign from their job soon after they are diagnosed with cancer. If you are thinking of resigning, take your time and perhaps talk to a social worker or counsellor about your concerns.

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

Workplace changes

Employers have to take reasonable steps (called “reasonable adjustments”) to accommodate an employee’s illness and to help them do their job. Examples of reasonable adjustments include allowing additional breaks or modifying your workstation.

An employer can only refuse a request for reasonable adjustments if the changes would cause unjustifiable hardship to their business or on reasonable business grounds. If your request is refused, you can seek help from the Fair Work Ombudsman (visit fairwork.gov.au) or the discrimination agency in your state or territory (see page 59).

Flexible working arrangements

You have the right to ask for flexible working arrangements to help you manage your work. Usually, only employees who have worked for their employer for at least 12 months can request a flexible working arrangement. Employees covered by an Award may also have some extra rights when asking for flexible working arrangements. Flexible working arrangements differ on a case-by-case basis, but may include working from home some or all days or varying your hours.

Employers can only refuse a request for flexible working arrangements on reasonable business grounds. If your request is refused, you may seek help from the Fair Work Ombudsman (fairwork.gov.au), the Fair Work Commission (fwc.gov.au) or your state or territory discrimination agency.

Taking leave

All full-time employees are entitled to a minimum of 10 days of paid personal leave each year. This leave can be taken when you are unwell or need to care for an immediate family or household member. Personal leave for part-time employees is calculated on a pro rata basis. Employees can take as much personal leave as they have built up (accumulated), though your employer can ask you to provide evidence of your illness. Casual employees are not entitled to paid personal leave.

If you need to take more time off work, you may be able to combine personal leave with annual leave or long service leave, or ask your manager if you can take unpaid leave. For more information about your leave entitlements, visit fairwork.gov.au.

Discrimination

Discrimination in the workplace due to cancer and its treatment is generally unlawful. This includes denying you a promotion, demoting you to a lower paid position, dismissing you or refusing to hire you for a reason related to cancer. An employer may be able to lawfully discriminate against you, if you are unable to do the key parts of your job in the foreseeable future due to cancer or its treatment.

If you feel you've been treated unfairly, talk to your employer. If you're not happy with the response, you can lodge a complaint with your state or territory discrimination agency (see opposite page) or the Australian Human Rights Commission (humanrights.gov.au).

If you have experienced discrimination, harassment or other disadvantage due to your cancer diagnosis, you may also be able to lodge a complaint with the Fair Work Commission (fwc.gov.au). Most complaints can be resolved through mediation or conciliation (an informal way to negotiate an outcome). If this isn't successful, you may go to an administrative tribunal or to court for a legal judgment.

Unfair dismissal

If you feel you have been unfairly dismissed from your job, you may be able to lodge an unfair dismissal claim with the Fair Work Commission. You must lodge claims within 21 days of being dismissed and meet some other conditions (see fwc.gov.au for eligibility requirements). For more information, see our *Cancer, Work and You* booklet.

Discrimination agencies

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

Key points about legal and financial issues

Insurance

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

Finances

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

Workplace

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



Rights of carers

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

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

Talking to the treatment team

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

Making decisions

The person you care for may give you the power to make decisions on their behalf if they lose the capacity to make their own decisions (see page 39). This can include decisions about finances and medical care.

It is important that you have a discussion ahead of time about how much treatment the person wants for the cancer, what matters most to them when making treatment decisions, and whether you're able to carry out their wishes.

If the person you are caring for becomes incapable of making their own decisions and has not given you the power to make decisions on their behalf, the medical practitioner will approach the default substitute decision-maker. This may be you, if you are a spouse, partner, close family member or friend. For more information on this and on advance care planning, see pages 38–39.

Workplace issues for carers

Many people who care for someone with cancer are also employed. Sometimes people find it difficult to balance their working role with their caring role. You may need to take time off work or to stop working for some time.

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

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 are protected, you may want to inform the treating doctor that you are the patient's domestic partner, and are likely to be the default substitute decision-maker for medical decisions (see page 39).

You or your partner may be concerned about you being recognised as the decision-maker. If so, consider asking your partner (when they still have capacity) to appoint you as their substitute decision-maker (see page 39).

► For more information, see our *LGBTQI+ People and Cancer* booklet.

Taking time off work

All full-time employees are entitled to a minimum of 10 days of paid personal leave a year. This can be used if you are caring for a member of your immediate family or household who is sick. Personal leave for part-time employees is calculated on a pro rata basis. Employees can take as much personal leave as they have built up (accumulated), though employers can ask for evidence about why time off is needed (e.g. a medical certificate or a statutory declaration).

In addition, full-time and part-time employees are entitled to 2 days of paid compassionate or bereavement leave when an immediate family or household member is seriously ill or injured, or dies. Casual employees are also entitled to this leave, but it is unpaid.

If you've used all of your paid personal leave, or you are a casual employee, you are entitled to 2 days of unpaid carer's leave for each time a member of your immediate family or household requires care or support because of illness. If you need to take more time off work, you may be able to use annual leave or long service leave, or apply for leave without pay (if your employer allows this). For more information, visit fairwork.gov.au.

Flexible working arrangements

You may have the right to ask your employer to change your work arrangements to help you manage your work and caring responsibilities. The request must be made in writing. Employers can only refuse to provide these arrangements on reasonable business grounds. Examples of possible flexible working arrangements include:

- allowing you to work from home some or all of your working hours
- changing your start, finish or break times
- allowing you to vary your hours, work part-time or job share.

Discrimination

It is generally unlawful for your employer, or a prospective employer, to discriminate against you because of your caring responsibilities. You have the right to the same opportunities for promotion, transfer or training, and the same benefits as other employees, despite your caring responsibilities.

Making a complaint

If you feel you have been discriminated against or treated unfairly 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 59). See pages 58–59 for further details on making a complaint about discrimination in the workplace.

Support and financial assistance for carers

Being a carer can bring a sense of satisfaction, but it can also be stressful and challenging. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your GP, or call Cancer Council 13 11 20. There is a wide range of support available to help you with your caring role, including respite care. The Australian Government's Carer Gateway provides practical information and resources for carers. Call 1800 422 737 or visit carergateway.gov.au.

Caring for someone with cancer can also cause financial difficulties. Services Australia (Centrelink) supports carers with a range of payments, including the Carer Payment and Carer Allowance. For more information about these payments, call 132 717 or visit servicesaustralia.gov.au.

Key points about carer rights

Treatment-related

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

Workplace-related

- You may be able to take leave if you need time off work to care for someone in your family or household. Leave options include personal leave, annual leave, long service leave and unpaid leave.
- You can request flexible working arrangements to help you manage your work and caring responsibilities. Employers are legally obliged to consider all requests and may only refuse requests where they have reasonable business grounds for doing so.
- Discrimination at work because of your caring responsibilities is generally unlawful.
- If you've been discriminated against, you may be able to make a complaint to the Australian Human Rights Commission, the Fair Work Commission or the human rights or discrimination agency in your state or territory.

Support for carers

- Services Australia (Centrelink) supports carers with a range of payments, including the Carer Payment and Carer Allowance.
 - Support services, such as counselling and respite care, are available for carers of all ages.
-

Support and information

Useful websites

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

Cancer and health care organisations

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Guides to Best Cancer Care	cancer.org.au/ cancercareguides
Australian Commission on Safety and Quality in Health Care	safetyandquality.gov.au
Department of Health and Aged Care	health.gov.au
MyHospitals	aihw.gov.au/myhospitals
Pharmaceutical Benefits Scheme	pbs.gov.au
PrivateHealth.gov.au	privatehealth.gov.au
Services Australia (includes Centrelink, Medicare)	servicesaustralia.gov.au

Regulatory and complaints organisations

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

Support from Cancer Council

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

Cancer Council 13 11 20



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

Information resources



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

Legal and financial support



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

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

Peer support services



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

Question checklist

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

Choosing a specialist

- Have you treated a lot of people with this type of cancer?
 - Do you practise in the public or private system, or both?
 - Do you specialise in treating this type of cancer? If not, could you recommend someone who does?
 - Do you work in a multidisciplinary team? Who else is in the team?
 - I'm thinking of getting a second opinion. Can you recommend anyone?
-

Treatment choice, side effects and informed consent

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

Financial impacts and complaints

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

Glossary

advance care planning

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

advocacy

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

allied health professional

A university-qualified professional who works with others in a health care team to support a person's medical care. Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

alternative therapy

Any of a range of therapies used in place of a conventional treatment, often in the hope that it will provide a cure.

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 make decisions and understand the impact of those decisions.

clinical trial

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

code of conduct

A list of professional rules that health care

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

complementary therapy

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

conciliation

See mediation.

consent

When you agree to something.

enduring power of attorney/enduring power of guardianship

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

evidence-based medicine

When health care providers make decisions based on research 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 payment

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.

health care rights

Rules and guarantees for people receiving health care, covered in the Australian Charter of Healthcare Rights.

health service

An organisation that provides a health service and holds health information.

informed consent

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

informed financial consent

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

inpatient

A patient who stays in hospital while having treatment.

insurance

A contract between a company and an individual that guarantees a payment in the case of covered events.

mediation

An informal type of resolution using a mediator or negotiator who communicates between 2 parties to settle differences and problems. Also called conciliation.

medical negligence

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

medical record

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

multidisciplinary care

A system where all members of the treatment team work together to discuss a patient's physical and emotional needs, and decide on which treatment to recommend.

National Board

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

out-of-pocket costs

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

outpatient

A patient who visits hospital for medical care without being admitted into hospital.

pathologist

A specialist doctor who interprets the results of tests such as blood tests and biopsies.

patient responsibilities

Expectations that patients treat their health care team with respect, honesty and consideration.

patient rights

See health care rights.

PBS Safety Net

Government scheme to reduce the cost of prescription medicines for individuals and families once the PBS Safety Net threshold has been reached.

personal/carer's leave

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

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 hospital cover can choose their own doctor

and whether they want to be treated in a private or public hospital.

public guardian

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

radiologist

A specialist doctor who analyses x-rays and scans.

registered health professional

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

registrar

A hospital doctor who is training to be a specialist.

resident medical officer

A hospital doctor who has not undertaken specialist training.

respite care

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

schedule fee

Medicare's set fee for a medical service.

screening

An organised program to identify disease in people before any symptoms appear.

specialist

A doctor with qualifications and skills in a particular branch of medicine (e.g. an oncologist is a doctor who specialises in the study and treatment of cancer).

stage

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

substitute decision-maker

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

unfair dismissal

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

unregistered health practitioner

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

Can't find a word here?

For more cancer-related words, visit:

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

References

1. Australian Commission on Safety and Quality in Health Care, *Australian Charter of Healthcare Rights* (second edition), viewed 7 November 2022, available from safetyandquality.gov.au/your-rights.



How you can help

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

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

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

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

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

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

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



Cancer Council

13 11 20

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

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

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

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



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



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

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

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

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council Queensland
cancerqld.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council NSW
cancercouncil.com.au

Cancer Council SA
cancersa.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Tasmania
cancer.org.au/tas

Cancer Council Australia
cancer.org.au

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

