

Cancer Care and Your Rights

A guide for people affected by cancer

Everyone has certain rights and responsibilities when accessing health care in Australia. Knowing your rights helps you better understand your care and be more involved in decisions about your health.

What are health care rights?

The Australian Charter of Healthcare Rights¹ explains the 7 key rights for people receiving health care in Australia. You have a right to:

- access health care services and treatment
- receive safe care
- be treated with respect
- take part in decision-making
- receive clear information
- have your privacy protected
- give feedback.

Why are rights important?

Knowing your rights helps you understand what to expect and how to take an active role in your care. You have the right to ask questions and get the information and support you need.

Person-centred care means your care is based on what matters to you. This includes your needs, preferences and values, and the needs of your family and carers. It helps your health care team understand your goals and include you in decisions. Making joint decisions about your treatment and care can lead to better results.

If you don't feel comfortable speaking up, a support person may be able to assist you or call Cancer Connect 13 11 20 for more information.

How are health care rights protected?

Everyone who works in a health service must respect health care rights. This helps make care safe, high-quality and person-centred.

Some rights are protected by law. These laws cover unfair treatment (discrimination), medical care, professional behaviour, and privacy. Health professionals and health care services must follow these laws. Other health care rights describe what you can reasonably expect from your care, for example, getting a second opinion.

“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

Is discrimination unlawful?

Yes. In Australia, laws protect you from discrimination. Health services can't treat you unfairly because of who you are. This includes your age, disability, race, sex, intersex variations, gender identity or sexual orientation.

- ▶ See our *LGBTQI+ People and Cancer* booklet for specific challenges you might face.

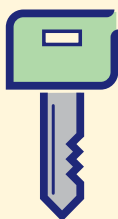


For an overview of what to expect during all stages of your cancer care, visit cancer.org.au/cancercareguides. These short guides give recommended approaches to diagnosis and treatment for a range of different cancer types and situations.

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

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 needed, you should get instructions about how to safely care for yourself at home.

Privacy



You have a right to privacy when you receive health care. 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.

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.

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 get a second opinion and to have access to your own health information.

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 any clinical trials offered to you. You have the right to include family members and carers in your decision-making and meetings with doctors if you wish.

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.

Informed financial consent

In Australia, health care providers set their own fees. Before treatment starts, your doctors and other health care providers will usually talk to you about the likely fees (called out-of-pocket costs). This is called informed financial consent. You can ask questions if something is not clear, and you can ask for this information in writing, so you can refer to it during your treatment.

There may be extra costs associated with your treatment that you did not expect. For example, if you have surgery as a private patient, you may pay for your stay in hospital and for the anaesthetist, as well as for the surgical procedure.

Sometimes it is not possible to give informed financial consent before medical care, such as in an emergency. If this happens, you should be asked for consent as soon as it is practical afterwards.

Exploring medical costs

The Australian Government's online tool [Medical Costs Finder](#) 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.

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.

Services Australia (Centrelink) offers a range of payments that may be available to people with cancer. Talk to your social worker or visit servicesaustralia.gov.au.

Informed consent for treatment

Your doctor and treatment team will help you make informed decisions about treatment. They will usually explain:

- 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, you can ask the doctor if they can arrange one or call the Translating and Interpreting Service on 131 450.

When you understand this information and agree to treatment, this is called informed consent. You will usually be asked to sign a form showing that you understand the information you have been given and agree to treatment. If you have questions or need more information, talk to your doctor.

Usually, you can change your mind even if you have already given consent. Make sure you tell your doctor or other health care professional clearly if you change your mind.

To agree to treatment, you must have capacity. Capacity means you can:

- understand the choices available to you
- remember the information given to you
- understand the outcomes of your decision
- communicate your decision.

If you do not have capacity, another person may be able to make decisions for you. In a case of a medical emergency or where you are unconscious or unable to make decisions, consent may not be needed. 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 our fact sheet *Advance Care Planning*.

Consent from children

A parent or guardian usually makes health care decisions for their child. Children should still be involved as much as possible in these decisions. It is important to ensure that the health care team considers your child's health care preferences.

A child should be given age-appropriate information, take part in discussions about their treatment, and be encouraged to ask questions.

A child may be able to make their own health care decisions and consent to treatment if certain conditions are met. Different states have different laws around this.

Feedback

Feedback helps to improve care. It lets health services know what is working well and what could be improved, and it helps keep care safe. You can share positive feedback through compliments, and offer suggestions for ways your treatment experience could be made better.

All health care services should have ways for patients to give feedback and make complaints. Check with the cancer care coordinator, clinical 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 happened, and talking about it may help you understand what is happening and could make you feel better about your situation. You can also ask a friend or relative to raise a concern for you.

If you don't feel comfortable raising the issue directly, or you weren't happy with the initial discussions, you may prefer to send an email or write a letter. If you write your complaint, you may need to wait for a reply. Health professionals must keep any complaints you lodge private, unless an exception (such as mandatory reporting) applies.

If you have concerns about your private 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).

Health care complaints

You can give feedback or make a complaint about your health care whether you are treated in a public or private hospital or treatment centre, or if you see a practitioner in a private clinic. Complaints will be managed differently depending on the type of concern and the state or territory where you are having care.

Health services are also expected to acknowledge patient harm by telling you if something has gone wrong during your care, how it may affect you and

what is being done to make care safe. Ask your health service if it has a policy around providing this information and what the steps are under their policy.

For more information, visit safetyandquality.gov.au and search for "open disclosure guide for patients"

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 below). It can be helpful to check if there are any time limits or other requirements you have to meet before making a complaint.

Health complaints organisations	
National	Aged Care Quality and Safety Commission 1800 951 822 agedcarequality.gov.au
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 hccsc.nt.gov.au
QLD	Office of the Health Ombudsman 133 646 oho.qld.gov.au
SA	Health and Community Services Complaints Commissioner 1800 232 007 hccsc.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

Health care complaints should be in writing and can often be made by filling in an online form. If you can't 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 give 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 access 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 health complaints organisation 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.



Issues relating to public health and safety are raised 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 such as the Australian Health Practitioner Regulation Agency (ahpra.gov.au) for further consideration.

Medical negligence

Health professionals must treat you safely and with care and skill. If you have been injured or have 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:

- not diagnosing or treating you promptly
- not advising you of risks of procedures
- giving you the wrong medicine.

Medical negligence claims about cancer diagnoses and care are not common.

In most states and territories, you can generally make a negligence complaint up to 3 years from the date when the injury occurred. Exceptions may apply where an injury was not discovered until later.

The process of proving negligence can be hard and expensive. You may have to go to court. 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.

Workplace issues

Telling your workplace that you have cancer is your choice and you may choose not to tell your workplace about your diagnosis. However, it can be helpful to talk to your employer if you can't work or you need some changes to help you continue doing your job or return to work.

You must tell your workplace if your health affects safety or your ability to do your job.

You may be concerned about your leave entitlements, or about being discriminated against, your working hours being changed, or being let go 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 an employment lawyer who specialises in employment matters.

Some people leave work or stop working 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.

You may also find it helpful to speak with a financial counsellor to discuss how stopping work could affect your financial situation.

To talk to a financial counsellor, phone the National Debt Helpline on 1800 007 007 or visit ndh.org.au.

- ▶ See our *Cancer, Work and You* booklet, or our workplace fact sheets.

“At the time of diagnosis, I was working as an office manager, but afterwards we reassessed our life. I changed jobs and we moved house. I now work in aged care, which I love.” JODIE

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. Knowing your rights as a carer can help you communicate with the treatment team.

As a carer, one of your key roles is to help the person you care for talk 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. 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.

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 human rights, equal opportunity or anti-discrimination agency in your state or territory or the Fair Work Commission (fwc.gov.au).

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



Your responsibilities as a patient

Health professionals understand that dealing with cancer is challenging and many people feel vulnerable at this time. It is important to build a trusting relationship with your health care team.

Treat your health care team with respect, and expect the same from them. Many hospitals and treatment centres have guidelines on patient responsibilities that cover 3 areas: being considerate; being honest and open and being flexible.

Being considerate

These responsibilities relate to practical issues while on-site, 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 or keeping the area smoke free
- asking permission if you would like to record consultations.

Being honest and open

It is important that your health care team has all the information they need to offer you the best possible treatment.

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.



Find out more about digital health records and privacy at digitalhealth.gov.au. You can also access information, data and health reports about all Australian hospitals from aihw.gov.au/myhospitals.

Being flexible

Your doctor will recommend treatment based on your initial test results, your overall health and the cancer care guidelines. 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 happen, 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. Waiting for treatment can be stressful – if you are anxious, speak to your doctor or call Cancer Connect 13 11 20.

Questions for your doctor

This checklist may be helpful when thinking about the questions you want to ask.

- 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?
- What are my treatment options? What is the aim of each treatment?
- Are there other treatments that you aren't recommending? Why?
- Are there any out-of-pocket costs not covered by Medicare or my private health cover?
- Who can I talk to if I have concerns about my care?

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

Where to get help and information

Call Cancer Connect on 13 11 20 or visit the website for more information about cancer and health care. Qualified professionals can listen to your concerns, put you in touch with local services and send you free copies of our booklets. You can also visit your local Cancer Council website.

Cancer Connect	cancerconnect.org.au
ACT	actcancer.org
NSW	cancercouncil.com.au
NT	cancer.org.au/nt
QLD	cancerqld.org.au
SA	cancersa.org.au
TAS	cancer.org.au/tas
VIC	cancervic.org.au
WA	cancerwa.asn.au
Australia	cancer.org.au

Other useful websites

Australian Health Practitioner Regulation Agency	ahpra.gov.au
Australian Commission on Safety and Quality in Health Care	safetyandquality.gov.au
Department of Health, Disability and Ageing	health.gov.au
Community Legal Centres Australia	clcs.org.au/legal-help

Note to reader

Always consult your doctor about matters that affect your health, a financial adviser or financial counsellor about matters affecting your finances, and a lawyer about legal matters. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice.

All care is taken to ensure that the information in this fact sheet 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 fact sheet.

