

Protecting Your Health Information

A guide for people affected by cancer

This fact sheet has been prepared to help explain your rights whenever your health information is collected and shared.

When you receive health care, you have a right to privacy and confidentiality. This means that health professionals must usually ask your permission before they collect or share your health information. Your health service provider should explain to you why they are collecting your health information and how they plan to store, protect and use it.

Laws in each state and territory protect your health information. For specific information on privacy laws that apply to Commonwealth government agencies and the private sector, contact the Office of the Australian Information Commissioner at oaic.gov.au, talk to your treatment team, or talk to a lawyer.

Who owns my health records?

The health service or health professional who creates a health record owns and maintains the record. However, under Australian law, ownership and access are different. Even though you don't own the health record, you generally have a right to see it or get a copy of it, unless an exception applies.

Health records must be kept safe. They must not be shown (disclosed) to people except for a permitted purpose (such as medical treatment) without consent and they need to be disposed of securely.

Different states and territories may have different requirements for how long doctors and health care providers must keep your records after your last consultation, or, for a child, after they turn 18, or 7 years after the last treatment, whichever is later.

What are health records?

When you receive health care, the person caring for you writes notes about your care. This is called a health record. It can be handwritten or electronic and may include:



Personal information

Personal details (e.g. your name, medical history, genetic information)



Health information

Information or opinions about your health or illness



Test results

Scans, tests and the comments on the results



Medical information

Recommendations about treatments and medicines



Medical collaboration

Correspondence with other health professionals about your care



Supporting information

Photographs, audio files or video footage

Every health service you visit will keep a health 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.



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

Who can access my medical records?

Health records are private and confidential. Health professionals directly involved in your care can view and use your personal and medical information. They should only do this when it's necessary or reasonably expected to be used for their work.

The Australian privacy principles say generally that health care providers must let you see the information they hold about you when you ask to see it. This includes your health records.

Giving people access to their health records has many benefits. Some of these include:

- helping them better understand their condition and treatment
- checking their information is accurate
- making you feel more confident about the health care system.

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

How to access your health information

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

There is no fixed time limit for providing health records, but providers should respond within a reasonable time.

The Office of the Australian Information Commissioner recommends responding within 30 days, while some of the state and territory privacy laws have set time limits.

The health care provider may charge a “reasonable” fee to copy your record based on the size of the record, or to recover other costs involved in providing access, but there shouldn't be a fee to request access in most cases.

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

If access is denied

In rare cases, you may not be able to get a copy of your medical records. This may happen if giving you access could seriously harm you or the privacy of another person who is mentioned in the record.

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 wrong, missing information, out-of-date, irrelevant or misleading, you can ask for changes. You may be asked to make this request in writing.

If a health service refuses to change your medical record because they think the record is correct as it is or that your suggested changes are not appropriate, the health service must explain the decision in writing. 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.

- ▶ See our *Cancer Care and Your Rights* fact sheet for information about making a health care complaint.



To find organisations in each state and territory that may be able to assist you with a legal problem, contact a community legal service, clcs.org.au/legal-help.

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, medical conditions and treatments). You and your health care providers can see your health information in one place. Insurers and employers are not able to access My Health Record without your permission.

My Health Record is automatically created for you and 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 digitalhealth.gov.au.

Questions for your doctor

You may find this checklist helpful when thinking about the questions you want to ask your doctor. Consider taking a support person with you – this could be a family member or a friend – to help you record and remember the answers.

- What information are you collecting?
- What do you plan to use this information for?
- Do you have a privacy policy? Can I have a copy?
- What is the process for me to access my health information?
- Is there a fee to access my information?
- Will you share my information with my specialists or other doctors?
- What is the process for changing my health information?

Acknowledgements

This information was developed with help from a range of health and legal professionals, and people using Cancer Council services. We thank the reviewers of this edition: Elena Schiena, Social Work – Clinical Lead, Peter MacCallum Cancer Centre, VIC; Tracey Bilson, Consumer; Tarishi Desai, Manager – Treatment and Supportive Care, McCabe Centre for Law and Cancer, VIC; Sarah Flynn, 13 11 20 Consultant, Cancer Council SA; Kim Greco, Lung Cancer Nurse Consultant, Flinders Medical Centre, SA; Dr Catherine Joyce, National Manager, Advance Care Planning Australia; Hall & Wilcox Lawyers; Linda Magann, CNC Palliative Care, St George Hospital, NSW; Joanna Page, Consumer; Brian Stace, Consumer; Dr Sabine Wardle, Senior Social Worker, Embrace Care Solutions and Charles Sturt University, NSW. We would also like to thank the health professionals and consumers who have worked on previous versions of this information.

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



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 Commission on Safety and Quality in Health Care	safetyandquality.gov.au
Commonwealth Ombudsman	ombudsman.gov.au
Australian Human Rights Commission	humanrights.gov.au
Australian Health Practitioner Regulation Agency	ahpra.gov.au

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.