

Older people with cancer

Your guide to best cancer care



About this guide

Being told you have cancer or could have cancer can be overwhelming. A lot can happen quickly, and you might have lots of questions.

This resource is for older people with cancer. It will help guide you, your family, carers and friends through this experience.

In Australia, government organisations use the term 'older' to refer to people aged 65 years and beyond. For Aboriginal and Torres Strait Islander people, the term is used for those aged over 50. But everyone ages differently, and a person's age in numbers may not reflect how well or unwell they feel. So it's important that your cancer team works with you to plan treatment and care that supports your needs and considers what matters most to you. This is called age-friendly care.

The Cancer Council website also has guides to best cancer care for different cancer types www.cancer.org.au/cancercareguides.

Information and support

The **OlderCan** resource www.wecan.org.au/oldercan has been developed with and is for older Australians affected by cancer. OlderCan offers advice and support to help you make decisions about treatment and care, and to make sure your GP and cancer team are aware of information that's important to you.

Cancer Council's Cancer Information and Support Service helps people affected by cancer with practical, financial and emotional support. It also helps you find your way to and around supportive care services. Call the Cancer Council on **13 11 20** to talk to a health professional or visit the website www.cancer.org.au for help or advice. For more information, look for a booklet on your cancer type in the Cancer Council's 'Understanding Cancer' series on its website.

Carers Australia is a national organisation that offers support, advice and information about services for carers who are caring for an older person with cancer. For support and advice for carers, call Carers Australia on **1800 242 636**.

Guides to best cancer care have been developed for Aboriginal and Torres Strait Islander people.

More information for Aboriginal and Torres Strait Islander people who might have cancer is on the Cancer Council website www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders/checking-for-cancer. You can also read the guide for Aboriginal and Torres Strait Islander people www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders/cancer on what to expect before, after and during your cancer treatment.

If you need an interpreter, call the **Translating and Interpreting Service** on **13 14 50** or visit their website www.tisnational.gov.au.

Initial tests and referral

Your general practitioner (GP) should do a check-up to see if they can find what's making you unwell. They'll ask you about any symptoms you might be having and may do some tests such as physical checks, blood tests, x-rays or scans.

Depending on the initial findings, your GP may refer you to a speciality team for further tests or treatment.



Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the specialist I see?
- How much will appointments cost me?
- How long should I expect to wait before I have an appointment?
- What should I do if I don't hear back about an appointment?

Diagnosis and staging

For some older people, age-related changes in heart or lung function, mobility or memory makes diagnosing cancer more challenging. This is especially the case if the symptoms from other illnesses look similar to, or become worse, because of the cancer.

The 'Your diagnosis' section of OlderCan www.wecan.org.au/oldercan/cancer-diagnosis focuses on the importance of sharing information with your cancer team. Sharing information can help ensure you get the treatment and care that's right for you.



Questions you might want to ask

- What other tests do I need to have?
- What type of cancer do I have?
- Can my cancer be cured? If not, what is the plan for my care?
- How long am I likely to live?

Treatment

When an older person is diagnosed with cancer, it's important that the cancer team finds out as much as possible about your health, how you function day to day and the things that are important to you.

This information can then be used to guide individual treatment choices.

Access to health services and support networks may also change as a person gets older. You might need extra help to manage your treatment and its side effects. Specialist aged care services can often provide that extra support for you and your carers alongside your cancer care team. You may wish to ask for a referral.

The OlderCan **This is Me** resource www.wecan.org.au/oldercan/cancer-diagnosis/this-is-me is one way you can share important information about your health, how you function and what matters most to you with your cancer team.

The 'Your Treatment' section of OlderCan www.wecan.org.au/oldercan/cancer-treatment might also be useful. It focuses on treatment choices, treatment types and what to consider when you're making decisions with your cancer team about the treatment that is best for you.

You can find information about diagnosis and treatment for different cancer types in the best cancer care guides www.cancercareguides.org.au.

Making treatment decisions

Regardless of your age, you have the right to know about all treatment options available to you. This will help you make the best decisions with your family or carer, and your cancer team. Some older people are not given this information. Sometimes this is a person's preference, but sometimes it's not.

Ageism is when older people are treated unfairly because of their age or because they are considered too 'old' or 'elderly' to be given information or to make decisions about their own care. Let your treating team know how much information you want and how involved you want to be in decisions about your care. You may decide to have treatment, to not have active treatment, or to only have some treatment to reduce pain and discomfort. You may want your family or other support people to come with you and be involved in talking about treatment options with your doctors. You may want to discuss your decision with other members of your healthcare team, GP, family and carer.

If you change your mind after deciding about treatment, let your doctors know. They'll be happy to talk through any concerns or questions you may have and to talk about other treatment options that may be better for you.



Timeframes

The timeframe for your treatment to start will depend on what's recommended for your cancer type. Visit the Cancer Council website for more information about timeframes for your type of cancer www.cancer.org.au/cancercareguides.

More information about cancer treatment choices is in the 'Cancer treatment choices' section of OlderCan www.wecan.org.au/oldercan/cancer-treatment/cancer-treatment-choices.

Clinical trials

You may be offered to take part in a clinical trial or you may want to ask your specialist if there's a clinical trial that's suitable for you. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials. For more information visit the Australian Cancer Trials website www.australiancancertrials.gov.au.

Complementary therapies and other medications

Speak to your healthcare team about any dietary supplements, vitamins, herbal remedies or other medications you use or would like to use, including prescription and over the counter medicines (e.g. paracetamol or ibuprofen). Some medicines, complementary therapies and vitamins might not work well with your treatment.

Advance care planning

Advance care planning is a process of thinking about what matters most to you when it comes to your future health care. If you were to become very unwell and not able to tell others what care or treatment you would want, think about who you would want to speak for you and what you would want them to say. Having these conversations while you feel well makes sure you can take time to think about the things that are important to you about medical treatment, health care and quality of life.

Advance care planning helps others understand what care or treatment you might want, that fits with your values, wishes and preferences. You can give advice about things like consent, refusing and withdrawing treatment in the future and/or appointing a substitute decision-maker. You can also set out more general wishes and preferences about your future health care, such as the people you would like around you, the music you like, or where you would prefer to be cared for. Advance care planning processes and documents differ in each state and territory. Find out more about advance care planning www.advancecareplanning.org.au online or by contacting the National Advance Care Planning Advisory Service on **1300 208 582**.

Advance care directive

An advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want to receive in case you become too unwell to make those decisions yourself. In some states and territories, this document may be used to formally appoint a substitute decision-maker.



Questions you might want to ask

- What is the goal of my treatment and care?
- What treatment do you recommend for me?
- Why do you think this is the best treatment for me?
- How long do you expect my treatment to continue?
- What side effects could I have from treatment?
- How will the treatment affect my day-to-day life?
- Will I be able to keep working?
- Who do I contact if I am feeling unwell or have any questions when I am away from the hospital?
- What help can I get if I am finding it hard to manage jobs at home when I'm having treatment?
- Where and how often will I have to go to the hospital to have treatment?
- Can I get transport to treatment appointments?
- What will treatment cost and how much of the cost will I have to pay myself?
- Can I still look after my husband/wife/grandchildren?
- Can I still carry on doing the things I enjoy or are important to me?
- How will this affect my family or those caring for or supporting me? Where can they get help or support?
- Can you direct me to information or services I can use to help me take care of myself?

Your healthcare team

A person with cancer might see one doctor or several different doctors and other health professionals depending on their cancer type, treatment options and care needs. Your doctor or nurse might suggest seeing a health professional who can help with information about:

- eating and nutrition
- moving around
- managing medications
- functioning at home or accessing support
- emotional care and support
- peer support.

Supportive care refers to all these aspects of your care and are an important part of your treatment and wellbeing. So if you feel you need help with anything, let your doctor or nurse know. You can ask for help or referral to supportive care services at any stage of your illness. These professionals are all part of your healthcare team.

You may want to talk privately with a member of the healthcare team about feeling safe in your own home or you may have concerns about control over your money. You can ask your doctor or nurse to make an appointment for you with a social worker who will listen to your concerns and give advice. They won't do anything or talk to anyone without your permission.

OlderCan has information about communicating with your healthcare team www.wecan.org.au/oldercan/cancer-diagnosis/communicating-with-your-team. You can use the OlderCan This is ME resource www.wecan.org.au/oldercan/cancer-diagnosis/this-is-me to let the team know you have concerns about being at home.

Your general practitioner

Your GP is an important member of the healthcare team who will care for you during and after your cancer treatment. If you have a good relationship with a GP before your cancer diagnosis, or you find a new GP after a cancer diagnosis, it's important to keep seeing them regularly.

The OlderCan This is Me resource www.wecan.org.au/oldercan/cancer-diagnosis/this-is-me can be used to share important information with your GP and cancer team.

OlderCan has more information about your health and your GP www.wecan.org.au/oldercan/your-gp/your-health-and-your-gp.



You can also ask your GP for a referral to another specialist for a second opinion.

Older carers

For many people, having a partner, family member, friend or carer who can support them throughout their cancer experience is very important. This person (or team) can make a big difference in a person's cancer journey.

When cancer occurs later in life, the main carer, whether it's a partner or friend, may also be an older person who may have their own health and wellbeing issues.

Carers provide incredible support such as emotional support, company and understanding. Carers also provide practical help, such as help with getting to or managing multiple appointments or medications.

OlderCan has more information about carers and support available www.wecan.org.au/oldercan/older-carers.



Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking. Healthcare providers are required to give you information about the cost of any treatment they recommend before you start treatment. This is called informed financial consent.

Speak with your GP, specialist, a financial counsellor or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be. If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment and information on benefits or entitlements to assist with treatment-related costs.

You can call the Cancer Council on **13 11 20** to speak to a health professional about financial support. The website also has information about:

- practical and financial assistance www.cancer.org.au/support-and-services/practical-and-financial-assistance
- paying for treatment www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment
- informed financial consent www.cancer.org.au/health-professionals/resources/informed-financial-consent.

Recovery

Cancer treatment can cause physical and emotional changes.

Your follow-up care plan

Your healthcare team will work with you to make a plan for your ongoing care. A copy of the plan should be given to you and your GP. If you are not given a plan for follow-up, ask your doctor or nurse if one is available. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- how to deal with any side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Some people may lose fitness and strength during their cancer treatment or have more difficulty with their memory or thinking. This may make it harder to manage day-to-day tasks. Many people worry that the cancer will return. Your specialist and healthcare team will talk with you about your needs and can refer you to other health professionals and community support services. Keeping active makes a big difference to your physical and emotional recovery. It can be as little as a 10-minute walk outside every day to start with.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

Visit the Cancer Council website for more information about support after treatment www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment.



Questions you might want to ask

- What are the goals of treatment now?
- Who should I contact if I'm feeling unwell?
- What can I do to keep my strength and fitness the best it can be during treatment?
- How can I build up my strength and fitness again after treatment?
- Where can I get more help to manage at home?

Living with advanced cancer

If the cancer returns

Sometimes cancer can come back after treatment. It can come back in the same place or can appear in a different part of your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

The kind of treatment you may have will depend on how far the cancer has spread, how fast-growing it might be, the symptoms you are experiencing and what matters most to you.

Visit the Cancer Council website for more information about advanced cancer www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment.



Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- What can you do to help manage my symptoms?
- Are there things I can do to help manage my symptoms?
- What extra support can I get if I'm on my own at home?
- What extra support can I get if my family and friends care for me at home?
- What support is available for my family or carer?

Palliative care

Palliative care helps people live their lives as fully and comfortably as possible at any stage of their cancer experience.

It is provided by a team of experts, alongside a person's usual care. It focuses on relieving symptoms and providing extra support to the patient and their family.

Palliative care is not just about treatment at the end of life. Many people with cancer and other serious diseases may receive palliative care and treatment for years to make sure their quality of life is the best it can be. This care may be at home, in a hospital or at another location you choose. OlderCan has more information about palliative care www.wecan.org.au/oldercan/cancer-treatment/palliative-care.



Speak to your GP or other health professional or visit the Palliative Care Australia website
www.palliativecare.org.au.

Voluntary assisted dying

A person with cancer that cannot be cured who meets strict requirements (e.g. how long they are expected to live or their ability to make their own decisions) may want to ask about or consider voluntary assisted dying. It must be voluntary and requested by the person themselves.

Voluntary assisted dying laws are different in each state and territory, so it's important to know the law and rules around this choice in the state or territory where you live. Contact your health department for the latest information for your area.



Team use (hospital number)

IMPORTANT INFORMATION FOR MY CARE TEAM

MY HEALTH

- I rate my health as **good / average / poor**
- I have **heart disease / arthritis / diabetes / breathing problems / kidney disease**
- Other health issues
- I take prescription medications a day
- I take supplements (e.g. vitamins) **yes / no**
- I have **lost / gained** weight in the last 3 months
- My hearing is **good / average / poor**
- My vision is **good / average / poor**
- I feel **anxious / depressed**
- I feel happy **often / sometimes / never**

PHYSICAL ACTIVITIES

- I can walk metres
- I use an aid (e.g. frame, stick, other) **yes / no**
 - I do some exercise **daily / weekly / never**
 - I can do **all / some / none** of my housework
 - I can do **all / some / none** of my shopping
- I have help with doing
- I had falls in the last 3 months
- I have a My Aged Care / Home care package **yes / no**

This is Me

Name

Preferred name

Age Gender

Language spoke

Born in

I have a regular GP
yes / no

WHAT'S IMPORTANT

- I enjoy
- My cancer team need to know that:
- Quality of life is **more / less** important than length of life for me
- I want to be involved in all treatment decisions **yes / no**
- I want someone with me at my appointments **yes / no**
- Other things that are important to me are

THINKING

- I can use a computer **yes / no**
- I use other devices (e.g. Smart phone) **yes / no**
- I manage my money **yes / no**
- My memory is **good / average / poor**

BEING WITH OTHERS

- I live in **my own house / retirement village / aged care home** or
- I live by **myself / with my partner / family / friends**
- I am able to spend time with other people when I want **yes / not always / no**
- Even with my cancer, things are OK at home **yes / no**
- I feel lonely **never / sometimes / often**



Completed by Date: www.oldercan.org

The information provided in this form has not been drawn from medical record and reflects the views of the person completing the form © 2024 V1

HOW TO USE THIS IS ME

This is Me was developed by older adults with cancer to prompt a conversation with members of their healthcare team about what matters most to people during their cancer experience.

It was developed to help people share information about their health, quality of life and personal preferences when decisions about cancer treatment and care are being made. It can be used with the hospital team, a GP, or anyone in a person's support network.

How to use *This is Me*

You can use *This is Me* once or many times across your treatment pathway. You can print and fill out the form yourself and take it with you to a hospital or GP appointment or ask your doctor or nurse to talk through the form with you.

Filling out *This is Me*

There are no right or wrong answers. Questions about whether you feel aspects of your health are good, average or poor are about how things feel to you now (today), rather than how you feel when you compare with other people. In each of the sections, please circle the answer that matches you and your health best.

How will the information be used?

Information from the form will help the team looking after you learn more about you, ask questions if they need more information and know if anything needs particular attention before you start treatment. This can help make sure that decisions about any future care fit with what matters most to you.

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Visit the **This is Me** webpage www.wecan.org.au/oldercan/cancer-diagnosis/this-is-me for more information on OlderCan. Use the form to help share information with your cancer team.

The OlderCan resource was developed by **WeCan** as part of the Older and Wiser project. The Older and Wiser project is a Cancer Australia *Supporting people with cancer* Grant initiative, funded by the Australian Government. The OlderCan resource is reproduced here with the permission of the University of Melbourne.

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, 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 above.

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