## 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. In Australia, the term old is used by government organisations to refer to people aged 65 and over and 50 years of age and over for Aboriginal and Torres Strait Islander people. However, there is a lot of variation in people's health as they age and a persons' numerical age may not reflect how well or not they feel. It is important therefore that your cancer team works with you to plan treatment and care that supports your needs, is age-friendly, and takes into account what matters most to you.

This resource has been developed for older people with cancer to help guide you, your family, carers and friends through this experience.

There is also information available to tell you what to expect for your type of cancer. You can find guides to best cancer care for different cancer types at <a href="https://www.cancer.org.au/cancercareguides">https://www.cancer.org.au/cancercareguides</a>

## Information and support

**The OlderCan resource** has been developed with and for older Australians affected by a diagnosis of cancer. The resource provides advice and support to help older people make decisions about treatment and care, and to make sure that their GP and cancer team are aware of information that is important to them <a href="https://wecan.org.au/oldercan/">https://wecan.org.au/oldercan/</a>

**Cancer Council:** For information and support, call Cancer Council on 13 11 20 to talk to an experienced healthcare professional or visit <a href="https://www.cancer.org.au">www.cancer.org.au</a>.

For more information about your cancer, look for a booklet on your cancer type in Cancer Council's Understanding Cancer series on your local Cancer Council website.

Carers Australia: 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. You can find information for Aboriginal and Torres Strait Islander people who might have cancer at <a href="https://www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders/checking-for-cancer">https://www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders/checking-for-cancer</a>. You can also find the guide for Aboriginal and Torres Strait Islander people on what to expect before, after and during your cancer treatment at <a href="https://www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders/cancer">https://www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders/cancer</a>

**Translating and Interpreting Service (TIS)** If you need a translator, call TIS on 13 14 50 or visit www.tisnational.gov.au.

## Initial tests and referral

#### Your symptoms and referrals

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

If your GP has concerns, you will be referred to a specialist at a public hospital or in private practice for more tests.

The timing of your specialist appointment should be within guidelines available for the kind of cancer you may have. You can find this information at:

https://www.cancer.org.au/cancercareguides. If you can't get an appointment within the time suggested for the type of cancer you may have, follow up with your GP.

#### 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?

## **Diagnosis and staging**

#### Your diagnosis and staging

For some older people, a diagnosis of cancer brings challenges linked to other health issues such as age-related changes in heart or lung function, mobility, or memory.

Access to health services and support networks may also change as a person gets older and extra assistance may be required to manage treatment and side-effects.

The "Your diagnosis" section of OlderCan focuses on the importance of sharing information between the person diagnosed with cancer and the cancer team. Sharing information can help ensure that older people have the most appropriate care and treatment for them. https://wecan.org.au/oldercan/cancer-diagnosis/

## Questions you might want to ask

- What tests will I have?
- What cancer type do I have?
- What stage is my cancer?

## **Treatment**

#### **Your treatment**

When an older person is given a diagnosis of cancer it's important that the cancer team finds out as much as possible about a person's health, how they function in the day to day and the things that are important to them. This information can then be used to guide individual treatment choices.

The OlderCan <u>This is ME</u> resource is one way you can share important information about your health, how you function and what matters most to you with your cancer team. <a href="https://wecan.org.au/oldercan/cancer-diagnosis/this-is-me/">https://wecan.org.au/oldercan/cancer-diagnosis/this-is-me/</a>

The "Your Treatment" section of OlderCan focuses on treatment choices, treatment types and what to consider when you are making decisions with your cancer team about the treatment that is most suitable for you <a href="https://wecan.org.au/oldercan/cancer-treatment/">https://wecan.org.au/oldercan/cancer-treatment/</a>

You can find information about diagnosis and treatment for different cancer types in the Best Cancer Care guides <a href="https://www.cancer.org.au/cancercareguides">https://www.cancer.org.au/cancercareguides</a>

## Making treatment decisions

Ageism is when older people are treated unfairly because of their age or because they are seen as "old" or "elderly." This can include attitudes and behaviours that others might hold about older people or that you hold about yourself, such as negative views of being older. Ageism might affect how others treat you or how you might expect to be treated by others. Regardless of your age, you have the right to know about all of the treatment options available to you. This will help you make the best decisions with your family or carer, and your cancer team. 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 will be happy to talk through any concerns or questions you may have and advise whether there may be other treatment options that may be more suitable for you. The timeframe for your treatment to start will depend on what is recommended for your cancer type. You can find information about timeframes for your type of cancer at: <a href="https://www.cancer.org.au/cancercareguides">https://www.cancer.org.au/cancercareguides</a>.

You can find more information about cancer treatment choices in the "Cancer treatment choices" section of OlderCan <a href="https://wecan.org.au/oldercan/cancer-treatment/cancer-treatment-choices/">https://wecan.org.au/oldercan/cancer-treatment/cancer-treatment-choices/</a>

#### **Clinical trials**

You may be offered to take part in a clinical trial. 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 <a href="https://www.australiancancertrials.gov.au">www.australiancancertrials.gov.au</a>

## **Complementary therapies and other medications**

Speak to your healthcare team about any dietary supplements, vitamins, herbal remedies, and other medications that 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

If you were to become very unwell and not able to communicate your preferences for treatment to others, consider who you would want to speak for you, and what you would what them to say. Having these conversations early makes sure that you can take time to think about the things that are important to you about treatment, care and quality of life.

Advance Care Planning helps you plan for your future medical treatment. It is an important process to help you to maintain choice and control of future decisions. You can provide directions about consent, refusing and withdrawing treatment in the future and/or appoint a substitute decision-maker. Find more information on advance care planning at <a href="https://wecan.org.au/oldercan/cancer-treatment/advance-care-planning/">https://wecan.org.au/oldercan/cancer-treatment/advance-care-planning/</a>

#### Advance care directive

Sometimes known as a living will, 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 in case you become too unwell to make those decisions yourself. For more information

visit <u>www.advancecareplanning.org.au</u>. Again, having these conversations early makes sure that you can take time to think about the things that matter most to you.

## Questions you might want to ask

- What treatment do you recommend for me?
- What is the goal of the treatment?
- What side effects could I have from treatment?
- How will the treatment affect my day-to-day life?
- 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 am 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/are important to me?
- How will this affect my family/those caring for or supporting me?
- Where can they get help or support?
- Can you direct me to information/services I can use to help me take care of myself?

#### **Your Healthcare Team**

A person with cancer might see one doctor or a number of different doctors and other healthcare professionals depending on their cancer type, treatment options and their care needs. Your doctor or nurse might suggest seeing a healthcare professional who can help with nutrition, mobility, managing medications, functioning at home or accessing support. You can ask your doctor or nurse to refer you for help with these areas of your wellbeing.

Some older people may want to talk confidentially with a member of the health care team about feeling safe in their own home or they may have concerns about control over their 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 be able to provide advice. They won't do anything or talk to anyone without your permission.

OlderCan has information about communicating with your healthcare team <a href="https://wecan.org.au/oldercan/cancer-diagnosis/communicating-with-your-team/">https://wecan.org.au/oldercan/cancer-diagnosis/communicating-with-your-team/</a> and the OlderCan <a href="https://wecan.org.au/oldercan/cancer-diagnosis/this-is-me/">This is ME resource</a> can be used to let the team know that you have concerns about being at home. <a href="https://wecan.org.au/oldercan/cancer-diagnosis/this-is-me/">https://wecan.org.au/oldercan/cancer-diagnosis/this-is-me/</a>

#### **Your GP**

A general practitioner (GP) is important for older people. A GP is a local doctor who cares for people of all ages, with many different health problems.

Your GP is an important member of the health care 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 him or her regularly.

The OlderCan <u>This is ME</u> resource can be used to share important information with your GP and cancer team. <a href="https://wecan.org.au/oldercan/cancer-diagnosis/this-is-me/">https://wecan.org.au/oldercan/cancer-diagnosis/this-is-me/</a>

Find more information about your health and your GP at OlderCan <a href="https://wecan.org.au/oldercan/your-gp/your-health-and-your-gp/">https://wecan.org.au/oldercan/your-gp/your-health-and-your-gp/</a>

You can 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 accompany and support them throughout their cancer experience is very important. This person (or team) becomes an important part of the person's life and can make a big difference in their cancer experience.

When cancer occurs later in life, the main carer, whether this is a partner or friend, may also be an older person often with their own health and wellbeing issues.

Carers everywhere provide incredible support and contribution to the care of people across Australia, providing practical help, such as help with getting to or managing multiple appointments or medications, and with emotional support through providing company and understanding.

Find more information about Carers and support available at OlderCan https://wecan.org.au/oldercan/older-carers/

#### **Decisions about cost**

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist 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 Cancer Council on 13 11 20 to speak to a healthcare professional about financial support.

For more information about costs, visit <a href="https://www.cancer.org.au/support-and-services/practical-and-financial-assistance">https://www.cancer.org.au/support-and-services/practical-and-financial-assistance</a> and

https://www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment.

## Recovery

#### **Your 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 you and your GP. 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
- understanding and dealing with 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 healthcare professionals and community support services.

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.

For more information visit

www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment.

## Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do 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.

For more information visit 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 am 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.

Provided by a team of experts, palliative care can be helpful at any time during the course of a serious or life limiting illness.

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 that 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. Find more information about Palliative Care at <a href="https://wecan.org.au/oldercan/cancer-treatment/palliative-care/">https://wecan.org.au/oldercan/cancer-treatment/palliative-care/</a>

Speak to your GP or specialist or visit www.palliativecare.org.au.

#### **Voluntary assisted dying**

A person who has cancer that can't be cured who meets strict requirements (such as how long they are expected to live or their ability to make their own decisions) can ask for access to voluntary assisted dying. It must be voluntary and requested by the person themselves.

As voluntary assisted dying laws are different in each state and territory, it is 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.

**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.

Published in XXX

This resource is based on information from the optimal care pathway for older people with cancer (1st edition), available at <a href="https://www.cancer.org.au/OCP">www.cancer.org.au/OCP</a>.

# [Add logos]

1



## IMPORTANT INFORMATION FOR MY CARE TEAM

MY HEALTH	PHYSICAL ACTIVITIES
• I rate my health as <b>good / average / poor</b>	• I can walkmetres
• I have heart disease / arthritis / diabetes /	• I use an aid (e.g. frame, stick, other) <b>yes / no</b>
breathing problems / kidney disease	<ul><li>I do some exercise daily / weekly / never</li></ul>
Other health issues	• I can do <b>all / some / none</b> of my housework
	<ul><li>I can do all / some / none of my shopping</li></ul>
I take prescription medications a day	• I have help with doing
• I take supplements (e.g. vitamins) <b>yes / no</b>	
• I have lost / gained weight in the last 3 months	
My hearing is good / average / poor	• I had falls in the last 3 months
My vision is good / average / poor	• I have a My Aged Care / Home
I feel anviewe / democracy	
I feel happy often / sometimes / never  This is Me  Name	
Preferred name	
Part 1	• I can use a computer yes / no
WHAT'S IMPORTANT Born in	• I use other devices
I have a regular GP (e.g. Smart phone) yes / no	
yes / no • I manage my money yes / no	
• My memory is <b>good / average / poor</b>	
My cancer team need to know that:  • Quality of life is <b>more / less</b> important than	
length of life for me	BEING WITH OTHERS
• I want to be involved in all treatment decisions yes / no	I live in my own house / retirement village / aged care home or
• I want someone with me at my appointments yes / no	• I live by <b>myself /</b> with my <b>partner /</b> <b>family / friend</b> s
Other things that are important to me are	• I am able to spend time with other people when I want <b>yes / not always / no</b>
	• Even with my cancer, things are OK at home yes / no
	• I feel lonely never / sometimes / often
We Can. Completed by Date: www.oldercan.org	



#### **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.