# People living in rural and remote areas with cancer

## Your guide to best cancer care

## About this guide

**People living in rural and remote areas often have strong community connections, enjoy unique social and environmental benefits and make significant contributions to Australia. More than seven million Australians live outside metropolitan areas. This guide to best cancer care supports people from rural and remote areas affected by cancer to receive the best care possible.**

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 can help guide you and family and friends through this experience.

## Information and support

**Angel Flight –** This volunteer organisation offers free, non-emergency flights and transfers to people living remotely to access specialist medical treatments. Your doctor can organise a referral. Telephone: **1300 726 567**. Website **www.angelflight.org.au**.

**Australian Commission on Safety and Quality in Health Care –** The commission has developed a guide explaining the care that patients should receive from their health service during cancer treatment. Website **www.safetyandquality.gov.au/consumers/understanding-your-rights**.

**Cancer Council –** Offering information and support, including financial counselling, psychological support, accommodation and transport. Telephone: **13 11 20.** Website: **www.cancer.org.au.**

**Cancer Connect –** Cancer Council's national cancer navigation service, designed to support people to navigate a complex cancer care system. Telephone: **13 11 20**. Website: **www.connect.cancer.org.au.**

**Canteen –** Canteen helps adolescents, young adults and parents to cope with cancer. Canteen offers individual support services, peer support services and a youth cancer service, as well as books, guides and useful links. Telephone: **1800 835 932** to talk to a health professional or **1800 226 833** for other enquiries. Website **www.canteen.org.au.**

**CareSearch –** CareSearch provides information about death and dying for the whole community. Website **www.caresearch.com.au**.

**Carer Gateway –** This Australian Government program offers free services and supports for carers. Telephone: **1300 422 737**. Website **www.carergateway.gov.au.**

**eviQ –** eviQ provides information for people having cancer treatment and their carers, families and friends. Website **www.eviq.org.au/patients-and-carers.**

**Healthdirect –** This government-funded service offers quality health information, advice and a service directory. Telephone: **1800 022 222**. Website **www.healthdirect.gov.au.**

**McGrath Cancer Care Nurses –** McGrath Cancer Care Nurses are registered nurses with specialist education and training in caring for people with cancer. Website **www.mcgrathfoundation.com.au/get-support/find-a-nurse.**

**Patient-assisted travel schemes –** These schemes offer financial assistance for costs associated with travelling for treatment. Schemes vary between states and territories. The National Rural Health Alliance has developed a fact sheet outlining the details of each scheme. Website **www.ruralhealth.org.au/publication/fact-sheet/patient-assisted-travel-schemes-guide.**

**Royal Flying Doctor Service –** The Royal Flying Doctor Service provides emergency medical and primary health care services to those living, working and travelling in rural and remote Australia. Telephone: **Emergency numbers vary between states** – visit the website to find the most appropriate number for you. Website **www.flyingdoctor.org.au.**

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

**WeCan –** An Australian supportive care website that helps people affected by cancer access information, guides and support services. Website **www.wecan.org.au.**



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## Initial tests and referral

### Symptoms

Your general practitioner (GP) (or healthcare provider) should do a check-up to see if they can find what is making you unwell. They will ask you about:

- any new or unusual changes in your body
- whether you are in pain
- how you are feeling
- whether anyone in your family has or had cancer.

If you notice any unusual changes in your body, it is important to see your GP (or healthcare provider) as soon as possible. Early detection of cancer can result in more successful treatment, better outcomes and better experiences of care.

### Initial tests you may have

A cancer diagnosis can take multiple appointments and tests. Some of the tests you might have include:

- **physical check –** an examination of your body to check for signs and symptoms of cancer
- **blood tests –** a sample of your blood will be collected to check your general health and to look for any signs that your organs (for example, your kidneys and liver) are functioning as they should be
- **x-ray –** an x-ray takes a picture of the area being investigated.

### Referrals

If your GP (or healthcare provider) has concerns, you will be referred to either a surgeon, oncologist, haematologist, radiation oncologist or other type of medical specialist at a public hospital, private hospital or in private practice for more tests. Not all hospitals offer the same services, so you might need to travel for your tests or to see a specialist. Speak with your health provider about your ability to travel to appointments and if you need extra support to travel. You may be entitled to financial assistance to support your travel. It is also important to discuss any other personal factors that might affect your ability to take part in treatment (for example, you live in a flood-prone area during the wet season).

You may be able to use telehealth for appointments and check-ups. This can help you get care quickly and reduce the need for travel. You can speak with your GP, nurse or healthcare provider about whether this might be a suitable option for you.

### Timeframes

The timing of your specialist appointment should be within recommended guidelines available for the kind of cancer you may have. You can find this information on the Cancer Council website **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 or health provider.

### Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- How can I choose the specialist I see?
- Can I request to see a specialist closer to home?
- How much will appointments cost?
- How often will I need to travel to see the specialist?

## Diagnosis and staging

The specialist will do more tests to see if you have cancer and the type of cancer you have. This process of working out if you have a medical problem is called making a **diagnosis**.

These tests will show exactly where the cancer is in your body, if it is growing, or if it has spread. This is called **staging**. Staging helps to work out the best treatment for you.

You might have one test or several tests.

The types of tests that you might have include:

- **Magnetic resonance imaging (MRI) scan.** A scan where a powerful magnet and radio waves are used to make a detailed picture of the body.
- **Positron emission tomography (PET) scan.** A small and safe amount of radioactive material is injected and your whole body is scanned to show where the cancer may be.
- **Bone scan.** A small amount of radioactive material is injected and taken up by areas of bone containing cancer.
- **Positron emission tomography – computed tomography (PET–CT) scan.** Computers and x-rays in combination with a small and safe amount of radioactive material injected into your veins are used to make a detailed picture of the body to see if there are any unusual areas of growth.

- **Computed tomography (CT) scan.** Computers and x-rays are used to make a detailed picture of the relevant area.
- **Image-guided needle core biopsy.** A sample of cells will be taken from a lump using a needle after local anaesthetic is used to numb the area. A CT scan or ultrasound is used to guide the biopsy needle.

Some of these tests may not be available locally, so you might need to travel. Ask your referring doctor for the closest location.

### Timeframes

Results should be available within the timeframe provided in the guidelines available for the kind of cancer you may have. You can find this information on the Cancer Council website **www.cancer.org.au/cancercareguides.**

If results are not provided to you in the time indicated by your health provider or in line with the guidelines for the type of cancer that you might have, follow up with your health provider.

### Questions you might want to ask

- What type of cancer do I have?
- What tests will I have? Do I need genetic tests to see if my family could be affected?
- How much will tests/appointments cost?
- Where should I be treated? Can I be treated closer to my home? Do I have a choice?
- How often will I need to travel for my care?
- What stage is my cancer?
- What support services are available to me?
- If I have treatment, will this prevent the cancer from coming back?
- How many, days, weeks or months of treatment will I need for my type of cancer?
- What can happen if I don't have treatment?
- How might this impact on my ability to work?

**You can ask your doctor for a referral to another specialist for a second opinion.**

## Treatment

There are several ways to treat cancer. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

This will include practical considerations about what treatments are accessible in your area and what travel will be required to get the best care. Discuss any travel concerns with your team.

You might have one treatment or a mix of treatments, and they may be given in any order depending on your circumstances:

- **Surgery** is where the cancer is cut out or removed. The type of surgery used will depend on where the cancer is and its size.
- **Radiation therapy** uses x-rays to kill cancer cells and stop the cancer growing. It may be given before or after surgery.
- **Chemotherapy** uses drugs to kill cancer cells and stop the cancer growing. It may be given either before surgery to try and shrink the cancer, or after surgery to stop it coming back.
- **Interventional radiology** – your radiologist uses imaging technology like ultrasounds, CT or MRI and tools like needles and catheters to deliver targeted treatments to the tumour.

For more information visit the Cancer Council website **www.cancer.org.au/cancer-information/treatment**.

Supportive care (treatment or services that support you through a cancer experience) are also available. This care is provided by a group of people that forms a 'multidisciplinary team' to provide care while you work your way through a cancer diagnosis and treatment. This team is made up of people with different roles – for example, cancer nurses, physiotherapists, occupational therapists, dietitians, social workers, cancer care coordinators and others. Due to workforce availability, this team might look different in different places and change if you are a private or public patient. Things this team might be able to help you with include:

- transport and accommodation if you need to travel for care
- information and guidance about employment, taking time off and returning to work – this can particularly impact people who are self-employed or casual workers, or those managing farms or small businesses
- coordinating your informal support network

- organising an interpreter and cultural services to make sure you feel safe, respected and understood (this also ensures your culture is considered and respected as part of your healthcare decision-making)
- supporting your emotional wellbeing to help you manage your emotional health and offer ways to help if you are feeling down or lonely
- support managing the technology to help you feel more comfortable using tools like telehealth (videocalls with your doctor) and checking whether you have access to the internet
- care and guidance for your loved ones to make sure your family and friends have the support they need – they often play a big role in your care
- managing your side effects – your treatment team will let you know what to expect. Side effects can vary among people – some people have many side effects, while others have very few.

## Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to find out whether new treatments are safe and may work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials. Some clinical trials are run in regional areas, but some are limited to metropolitan universities and hospitals. Although clinical trials require you to attend in person, using telehealth can make it easier for more people to take part in clinical trials, reducing the amount of travel. Discuss with your doctor whether a clinical trial might be an option for you.

For more information visit the Cancer Australia website **www.australiancancertrials.gov.au.**

## Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Complementary therapies can help you manage the physical and emotional effects of cancer and its treatment (for example massage and acupuncture). Some therapies can affect how other medical treatments work, so ask your doctor about therapies you might be considering.

### Timeframes

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 on the Cancer Council website **www.cancer.org.au/cancercareguides.**

### Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost?
- Will there be any out-of-pocket expenses? Can the cost be reduced or can I have the treatment elsewhere if I can't afford it?
- How long will I need to be away from home?
- Can I take a carer or family member with me?
- How will the treating team communicate with my local GP?
- Are there possibilities for funding support for travel and accommodation?
- Are there any possibilities to have my treatment, or some aspects of my treatment, delivered close to home?
- Should I change my diet and what activities/exercises will help me during and after treatment?
- Can I still work, drive and do my normal activities?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?
- Where are the clinical trials for my type of cancer mostly based?

**If there are factors in your life that will make treatment difficult for you (for example, living in a flood-prone area during wet season), it is important to share those challenges with your heathcare provider so other alternatives can be considered.**

## Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking. Accessing cancer treatment as a rural or remote patient can have extra costs if you need to travel to regional or metropolitan areas for treatment.

Speak with your GP, healthcare provider, 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
- getting a quote for care at a private hospital or clinic
- help with accommodation during treatment
- the possible financial impact of your treatment
- any travel support services in your area.

You can call the Cancer Council on **13 11 20** to speak to a healthcare professional about financial support or the National Debt Hotline on **1800 007 007** to get free advice from a financial counsellor.

The Cancer Council website has more information about financial assistance **www.cancer.org.au/support-and-services/practical-and-financial-assistance**, treatment costs **www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment** and employment considerations **www.cancer.org.au/support-and-services/cancer-work-and-you.**

You can also read a fact sheet about radiation therapy **www.targetingcancer.com.au/radiation-therapy.**

# Recovery

Cancer treatment can cause physical and emotional changes.

### Follow-up care plan

Your healthcare team will work with you to make a plan. This plan, which will also be provided to your GP (or healthcare provider), 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 and when to get help if you think the cancer has returned or is worse
- living through and recovering from cancer
- your ongoing medications, which might include hormone therapy: what to expect from side effects and how these will help you in the long run.

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.

Other information you may get:

- signs and symptoms to look out for if you are worried that the cancer has returned
- 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 the Cancer Council website **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 to be as healthy as possible?
- Where can I get more help?
- Can my GP give me a mental health plan to reduce the cost of seeing someone for emotional support?
- Can I get a referral to an exercise physiologist to help me to get my fitness and mobility back?
- Would a GP chronic condition management plan be appropriate for me?

# Living with advanced cancer

## If cancer returns

Sometimes cancer can come back after treatment. It can come back in the same place or can appear somewhere different in 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.

Treatment will depend on how far the cancer has spread, how fast-growing it might be, and the symptoms you are experiencing.

### 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?
- Is there a clinical trial available?
- Can I be referred for symptom support and palliative care support in hospital and at home?
- Where else can I get support?

## Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

## 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 the Advance Care Planning Australia website **www.advancecareplanning.org.au**.

## Palliative care

Your specialist may refer you to palliative care services. Palliative services can help at any stage of a life-limiting illness and doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

**Speak to your GP, healthcare provider, or specialist or visit or visit the Palliative Care Australia website www.palliativecare.org.au or the PalAssist website www.palassist.org.au.**

## Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer.

For more information visit the Cancer Council website **www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment.**

## Voluntary assisted dying

Voluntary assisted dying is an option in some Australian states and territories. You may wish to speak with your healthcare provider to understand the law where you live. You can find out more about voluntary assisted dying including information specific to where you live, on the Go Gentle website **www.gogentleaustralia.org.au.**

### Questions you might want to ask

- What can you do to reduce your symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

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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