Optimal care pathway for people living in rural and remote areas with cancer

FIRST EDITION

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Endorsed by

Australian Government
Cancer Australia

Cancer Council
Australia

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EQUITABLE CANCER OUTCOMES ACROSS RURAL AND REMOTE AUSTRALIA

Statement of acknowledgement

We acknowledge the Traditional Owners of Country throughout Australia and their continuing connection to the land, sea and community. We pay our respects to them and their cultures and to Elders past, present and emerging.

This work is available from the Cancer Council website <www.cancer.org.au/OCP>.

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Welcome and introduction

The *Optimal care pathway for people living in rural and remote areas with cancer* has been developed to improve equity of outcomes and experiences for people living in rural and remote Australia.

Most people living in rural and remote Australia view it as a privilege. Rural and remote Australian communities provide a range of social, environmental and lifestyle benefits to people living there, and the economies of many non-metropolitan areas have now diversified beyond the traditional agriculture, mining and energy sectors, providing increasing potential for growth and employment.

But the health outcomes for those living outside of metropolitan areas are well documented as below their urban peers. The challenges of delivering health care across the varied geography and demographics of Australia are elaborate and require sophisticated and bespoke solutions, with an understanding of the spectrum of rural and remote Australia and the interplay of distance, terrain, history, natural resources and opportunity.

This optimal care pathway does not aim to provide directed solutions for individual cancers, specific centres or even different regions but is a framework from which to create systems and local approaches to managing people with cancer outside metropolitan areas. It is intended for any health professional and health service who treats rural or remote Australians, including those working at large metropolitan or outer urban centres, as a backbone for service provision.

Optimal care pathways are endorsed by the Cancer and Population Screening Committee following advice from Cancer Australia's National Cancer Expert Group. Formal endorsement by the committee acknowledges the importance of this optimal care pathway and the responsibility of the health system to deliver care in an appropriate, culturally safe, responsive and coordinated manner to ensure access and that all Australians experience optimal health outcomes.

Cancer-specific optimal care pathways are to be used alongside this optimal care pathway. There is also an optimal care pathway for Aboriginal and Torres Strait Islander people with cancer, and the guides to best cancer care for consumers are available in different languages.

The diverse and innovative team creating this optimal care pathway comprised those with academic, nursing, medical, allied health, management and public health backgrounds, with representation from every state and the Northern Territory. Thank you to all the people and organisations who contributed to the design and review of this pathway.

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Summary

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

The optimal care pathways describe the standard of care that should be available to all cancer patients. The pathways support patients and carers, health systems, health professionals and services. They also encourage consistent, optimal treatment and supportive care at each stage of a patient's journey. Seven key principles underpin the pathways: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research and clinical trials.

This quick reference guide summarises the *Optimal care pathway for people living in rural and remote areas with cancer*.

Please note that not all patients will follow every step of the pathway.

Step 1: Prevention and early detection

Prevention

Effective cancer prevention strategies for people in rural and remote areas should focus on reducing risk factors and increasing access to services.

Health promotion activities include:

- healthy lifestyle choices
- immunisation
- increasing participation in screening programs
- increasing health literacy through education campaigns
- access to healthy food
- sun safety
- addressing food security concerns
- education and behaviour change, particularly emphasising recommended exercise levels, heart health and cancer prevention.

Preventive care includes access to affordable or subsidised options, including pop-up services (e.g. screening) and virtual care.

Risk factors

The risk factors for developing cancer are well established and people in rural, remote and lower socioeconomic areas have higher rates of cancer-related risk factors. It is important to consider and address these risk factors collectively.

Risk factors include:

- tobacco use (e.g. smoking)
- alcohol use
- overweight and obesity
- physical inactivity and sedentary behaviour
- dietary factors (e.g. low-fibre, processed foods)
- genetic risk factors
- infections (e.g. human papilomavirus, hepatitis B and C)
- co-existing medical conditions
- sun exposure
- environmental hazards (e.g. radiation, asbestos, chemicals).

Early detection

In comparison with metropolitan areas, people living in rural and remote areas may face extra disadvantages related to early detection, including:

- less access and availability of appointments
- less availability of screening services
- additional and longer travel to get to appointments
- lack of options and higher costs to access health care
- slower turnaround of results
- delays in follow-up.

Screening

The four population-based cancer screening programs available are the BreastScreen Australia Program, National Bowel Cancer Screening Program, National Cervical Screening Program, and National Lung Cancer Screening Program. Fewer people access these programs in rural and remote areas than in metropolitan areas.

Checklist

- ❑ Smoking status discussed and recorded, and brief smoking cessation advice offered to people who smoke
- ❑ Alcohol intake discussed and recorded and support for reducing alcohol consumption offered if appropriate
- ❑ Recent weight changes discussed and the patient's weight recorded
- ❑ Physical activity recorded
- ❑ Referral to a dietitian considered
- ❑ Eligibility for national cancer screening programs (breast, bowel, cervical and lung) checked, with appropriate referrals as needed
- ❑ Referral to a physiotherapist or exercise physiologist considered
- ❑ Education on being sun smart considered

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1: Prevention and early detection continued

Barriers to screening for rural and remote Australians include:

- longer travel distances to screening and follow-up services
- limited availability of female providers for breast and cervical screening
- cultural concerns and distrust in healthcare systems among Aboriginal and Torres Strait Islander peoples
- lack of knowledge and awareness of cancer screening
- health literacy challenges and not appreciating the value of preventive health care.

Screening recommendations

We need to ensure that people living in rural and remote areas, especially those with a high-risk or family history of cancer, have equitable access to screening programs.

Strategies to ensure equitable access to screening programs include:

- targeted education to the community and the health workforce
- culturally appropriate community engagement
- proactive patient navigation
- expanding mobile screening units
- integrating pre-screening and follow-up support via telehealth
- improving collaboration between local healthcare providers and tertiary centres.

Increased or high risk – refer to the cancer-specific optimal care pathway for screening recommendations.

Step 2: Presentation, initial investigations and referral

People living in rural and remote areas are more likely to have delays seeking help for symptoms than people in urban areas. This relates to lower levels of access and availability of services, attitudes and beliefs, levels of health literacy. Work responsibilities, including farming, seasonal or shift work are other important reasons why some people in rural and remote areas take longer to seek help for symptoms.

Coordinating investigations is important for people living outside major cities if these require travel. Returning for multiple visits to a centre can be burdensome, particularly for those who need to arrange accommodation, travel, childcare or work changes.

Referral options

At the referral stage, the patient's primary healthcare provider or other referring doctor should advise the patient about their options for referral, waiting periods, travel requirements, expertise, likely out-of-pocket costs and the range of services available.

- Establish the patient's preferences for where they would like to be referred. Include a discussion about public and private care, depending on whether the patient is privately insured, and about likely out-of-pocket costs.
- Understand the patient's preferences and resources to travel through diagnosis, treatment and follow-up. Explore eligibility for patient assistance travel schemes.
- Use available information provided by the local Primary Health Network on the HealthPathways portal, available in selected states and territories only.
- Consider a referral most appropriate to the patient's diagnosis, including:
  - local infrastructure of health services and treatment options
  - the need for coordination between primary and cancer specialist care providers
  - where the patient lives and what services are locally available, including access to allied health
  - access to diagnostic investigations and cancer specialist appointments
  - availability of care coordinators to help navigate complex systems.
- Ensure clear communication pathways are established between referring primary healthcare providers and cancer specialist services, including:
  - timely transfer of clinical information
  - prompt handover of discharge summaries and treatment plans
  - clear documentation of medication regimens.

Checklist

- ❑ Signs and symptoms recorded
- ❑ Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- ❑ Effective communication with the cancer specialist team (including specialist cancer nurse coordinators where applicable) ensured, including referrals and follow-up
- ❑ Referral options discussed with the patient and/or carer including cost implications
- ❑ Patient referred to support services (such as the Cancer Council or relevant cancer-specific non-government organisations) as required

Timeframe

Timeframes for completing investigations and referrals should be informed by the relevant cancer optimal care pathways and evidence-based guidelines. While access to care can be complex, clear pathways are needed to ensure timely investigations in rural and remote Australia.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 2: Presentation, initial investigations and referral continued

Communication

The primary healthcare provider's responsibilities include:

- explaining to the patient and/or carer who they are being referred to and why
- supporting the patient and/or carer while waiting for cancer specialist appointments
- informing the patient and/or carer that they can contact Cancer Council on 13 11 20
- ensuring effective communication with the cancer specialist team, including referrals and follow-ups.

Timeframe

Visit the Cancer Council website <www.cancer.org.au/OCP> for the optimal care pathways for each cancer type.

Step 3: Diagnosis, staging and treatment planning

Diagnosis and staging

Details for cancer staging are outlined in each cancer-specific optimal care pathway.

Rural and remote patients generally experience more advanced disease stages at diagnosis, although this varies across cancer type and rurality. Contributing factors to later-stage diagnoses include:

- limited access to diagnostic services
- longer distance to treatment facilities
- longer wait times for cancer specialist consultations
- fewer diagnostic tests performed.

With extensive travel for diagnostic workup, consider whether this is appropriate for each patient. Include a discussion with the patient about the travel requirements and whether this is appropriate for them.

Travel to some specialist centres for care may be arranged through a patient assistance travel scheme <www.healthdirect.gov.au/travelling-to-your-healthcare-appointment>.

Genetic testing, molecular profiling and pharmacogenetics

Molecular testing or profiling of the tumour may determine genetic variants.

Certain pathological subtypes of cancer or tumour tests (immunohistochemistry or tumour genetic tests) may suggest an underlying inherited cancer predisposition. Finding a germline mutation or an inherited gene fault will have implications for other members of the family.

Accessing genetic testing usually involves a face-to-face meeting and a formal informed consent process. This can reduce uptake, particularly for people in rural and remote areas where access to genetic counsellors can be limited.

Telephone and videoconferencing counselling sessions are increasingly used to allow access and to reduce travel time and cost.

In some states and territories, the treating team can offer 'mainstream' diagnostic genetic testing, after which referral is made to a familial cancer service if a pathogenic gene variant is identified.

Anyone diagnosed with cancer should have a detailed personal and family cancer history taken. Consult relevant guidelines <http://www.eviq.org.au/cancer-genetics/referral-guidelines> and refer patients to other treating centres for genomic testing as appropriate at any stage of the care pathway.

Molecular testing or profiling determines whether there are genetic variants (somatic mutations) in a person's cancer that can be targeted using specific treatments.

Pharmacogenetic testing uses a similar approach to determine genetic variants. This can lead to differences in the way certain medicines interact with the body. Pharmacogenetics can also determine the likelihood that a specific dose will be adequate and not toxic. Applying molecular and/or pharmacogenetic testing to inform treatment planning is required for many cancer types to ensure patients are prescribed the most appropriate treatment at the optimal dose.

Checklist

- ❑ Advance care planning discussed with the patient and/or carer
- ❑ Diagnosis confirmed
- ❑ Full histology obtained (remove if not relevant to cancer type)
- ❑ Performance status and comorbidities measured and recorded
- ❑ Patient discussed at an MDM and decisions provided to the patient and/or carer
- ❑ Clinical trial enrolment considered
- ❑ Supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
- ❑ Patient referred to support services (such as the Cancer Council or relevant cancer-specific non-government organisations) as required
- ❑ Patient referred to relevant cancer-specific OCPs
- ❑ Treatment costs discussed with the patient and/or carer

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 3: Diagnosis, staging and treatment planning continued

Treatment planning

Consider the following at the treatment planning stage:

- the patient's overall condition, life expectancy, personal preferences and decision-making capacity
- discussing the multidisciplinary team approach to care with the patient
- appropriate and timely referral to a multidisciplinary team meeting (MDM)
- pregnancy and fertility
- support with travel and accommodation
- teleconferencing or videoconferencing, including internet connectivity if needed.

Other factors to consider for people living in rural and remote areas include:

- geographical distance to treatment facilities
- seasonal challenges
- the nature of employment
- socioeconomic disparities
- access to supportive care services
- ensuring culturally safe care, access to interpreters and cultural practices that may influence care decisions
- psychosocial support and mental health care
- digital literacy and technology access
- caregiver support and capacity.

The multidisciplinary team should meet to discuss newly diagnosed patients before definitive treatment to recommend a treatment plan and to prepare for the post-treatment phase.

Virtual MDMs may help overcome geographical barriers and specialist shortages in rural areas. But virtual MDMs need ongoing attention to maintain team dynamics and technical infrastructure.

Lack of MDMs is a key reason for suboptimal cancer care for patients from rural and remote areas.

Research and clinical trials

Refer appropriate patients to other treating centres to take part in research, clinical trials or genomic testing at any stage of the care pathway. Be prepared to discuss the benefits and drawbacks of such trials. Any member of the multidisciplinary team can encourage cross-referral between clinical trial centres.

Search for a clinical trial <www.australiancancertrials.gov.au>.

Communication

The lead clinician's[1] responsibilities include:

- discussing a timeframe for diagnosis and treatment options with the patient and/or carer
- explaining the role of the multidisciplinary team in treatment planning and ongoing care
- encouraging discussion about the diagnosis, prognosis, advance care planning and palliative care while clarifying the patient's wishes, needs, beliefs and expectations, and their ability to comprehend the communication
- discussing accessibility of services, travel requirements, appropriateness of telehealth services and financial assistance that a patient may be entitled to
- providing appropriate information and referral to support services as required
- communicating with the patient's primary healthcare provider about the diagnosis, treatment plan and recommendations from MDMs.

Step 4: Treatment

Treatment decisions should respect patient preferences and logistics relating to travel, time spent away from home, competing commitments and culture. Rural and remote patients should not receive inferior treatment due to their geographical location but consider patient preferences.

Establish intent of treatment

- Curative
- Anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- Symptom palliation.

Checklist

- ❑ Intent of treatment established
- ❑ Risks and benefits of treatments discussed with the patient and/or carer

1 Lead clinician – the clinician who is responsible for managing patient care.
The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 4: Treatment continued

Barriers to receiving timely treatment for rural and remote patients are largely imposed by geographical locations and include:

- extended travel to access tests, surgeries, treatment and follow-up care
- potential loss of family and community support networks
- logistical complexity of organising appointments and travel arrangements
- lack of diagnostic equipment in rural and remote areas for pre-treatment testing
- healthcare workforce shortages in rural and remote areas
- limited access to multidisciplinary care teams
- financial stress associated with travel
- lack of knowledge around available support services to overcome geographical barriers.

Overcoming these barriers must be the priority of the treating team to ensure timely access to treatment. The following treatment options have extra considerations for rural and remote patients.

Surgery

Carefully consider access to postoperative care services during the treatment planning process, including their accessibility and cost.

Radiation therapy

Access to radiation therapy may be challenging for rural and remote patients. Telehealth and support with accommodation and travel can reduce barriers to access. Investigate regional radiation therapy centres <www.targetingcancer.com.au/find-a-treatment-centre>.

Systemic therapy

Tele-oncology and remote systemic therapy services have increased access to systemic treatment and should be explored as a treatment option. Despite advances, significant infrastructure and coordination challenges persist in some areas.

Where no medical oncologist is available to deliver treatment, less complex therapies may be delivered by a cancer specialist physician, primary healthcare provider or nurse with experience and training under the direction of a multidisciplinary team. This requires a detailed treatment plan and communication with a supervising medical oncologist or haematologist. Clinical management in rural and remote settings requires careful coordination between healthcare providers and cancer specialists to manage complex side effects, which becomes particularly challenging when patients are located far from specialty centres.

Targeted therapies and immunotherapy

Rural and remote patients face greater geographical difficulties accessing immunotherapy compared with urban patients. Socioeconomic factors and insurance status particularly affect lower-income patients.

Clinical management in rural and remote settings requires careful coordination between healthcare providers and cancer specialists to manage complex side effects. This becomes particularly challenging when patients are located far from specialty centres.

Emerging therapies

Increasingly, timely decision-making in oncology to choose the right treatment at the right time depends on specialised molecular or genetic testing of the tumour tissue to see if there are changes in the cancer cells that would predict a treatment's efficacy. These tests are beyond the standard histology and immunohistochemistry tests and take time to complete. The key principle for precision medicine is prompt and clinically oriented communication and coordination with an accredited laboratory and pathologist. There may also be increased costs associated with emerging therapies. This could take longer in regional and remote areas, therefore efficient logistics, clear communication between regional and metropolitan laboratories and access to telehealth consultations is crucial.

Checklist

- ❑ Treatment plan discussed with the patient and/or carer
- ❑ Treatment plan provided to the patient's primary healthcare provider
- ❑ Treating cancer specialist has adequate qualifications, experience and expertise
- ❑ Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- ❑ Patient referred to support services (such as the Cancer Council or relevant cancer-specific non-government organisations) as required
- ❑ Early referral to palliative care considered
- ❑ Advance care planning discussed with the patient and/or carer

Timeframe

Timeframes for treatment should be informed by evidence-based guidelines (where they exist) and relevant cancer optimal care pathways (if available) while recognising avenues to support quick access to investigations.

Visit the Cancer Council website <www.cancer.org.au/OCP> for the optimal care pathways for each cancer type.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 4: Treatment continued

Palliative care

Timely referral to palliative care can improve quality of life and referral should be based on the holistic needs of the patient and family, not prognosis. For more, visit the Palliative Care Australia website <www.palliativecare.org.au>.

Limited local palliative care services and long travel distances to cancer specialist providers can delay access to essential care. Some primary healthcare providers in rural and remote areas offer palliative support to patients. Consider exploring options for telehealth consultations and outreach services, alongside coordination with local healthcare providers to support both physical symptom management and psychosocial wellbeing. *The National palliative care standards for all health professionals and aged care services* <www.palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services/> provide a framework for delivering quality primary palliative care.

Communication

The lead clinician and team's responsibilities include:

- discussing treatment options with the patient and/or carer including the intent of treatment as well as risks and benefits
- discussing advance care planning with the patient and/or carer where appropriate
- communicating the treatment plan to the patient's primary healthcare provider
- helping patients to find support for exercise and other allied health programs where appropriate to improve treatment outcomes.

Other needs that may arise for rural and remote Australians living with cancer include:

- support managing extended travel and accommodation needs for treatment, particularly for those needing specialised care like radiation therapy
- help coordinating care between local providers and urban treatment centres
- help accessing telehealth services to reduce travel burden for suitable appointments
- financial support for costs related to travel, accommodation and time away from work
- connection to local support networks and patient navigation services to help coordinate ongoing care needs
- support for family caregivers who may need to travel or relocate temporarily to assist with care
- access to culturally appropriate psychosocial support services that consider rural and remote values and circumstances
- help managing treatment side effects with limited local cancer specialist support
- help coordinating follow-up care and monitoring between treatments.

Step 5: Care after initial treatment and recovery

The complexity of health systems means that services, organisations and providers often work independently to support people living with and beyond cancer. This may lead to fragmented care. Rural and remote people living with and beyond cancer face multifaceted challenges that require comprehensive, personalised approaches to supportive care that address their unique geographical, social and personal circumstances. Consider the following.

Provide a treatment and follow-up summary to the patient, carer and primary healthcare provider outlining:

- the diagnosis, including tests performed and results
- tumour characteristics
- treatment received (types and date)
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health professionals
- potential long-term and late effects of treatment and care of these
- supportive care services provided

Checklist

- ❑ Treatment and follow-up summary provided to the patient and/or carer and the patient's primary healthcare provider
- ❑ Supportive care needs assessment completed and recorded and referrals to allied health services actioned as needed

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 5: Care after initial treatment and recovery continued

- a follow-up schedule, including tests required and timing
- contact information for key healthcare providers who can offer support for lifestyle modification
- a process for rapid re-entry to medical services for suspected recurrence.

Considerations for people living with and beyond cancer transitioning from active treatment to survivorship care include:

- limited access to follow-up supportive cancer care due to cancer specialist shortages and/or long travel distances
- lack of trust in local rural and remote health care services
- higher rates of cancer-related fatigue, pain and the experience of poorer psychological outcomes than those from urban areas
- lower rates of receiving comprehensive survivorship care plans including unclear post-treatment pathways
- lack of information on prognosis and recovery, referrals to support services and lifestyle advice
- the need to reiterate information at multiple timepoints in an accessible way.

The transition from initial cancer treatment to survivorship care is critical to ensuring long-term health and wellbeing. These challenges may be more pronounced in rural and remote areas and/or patients may experience extra challenges.

When transitioning from active cancer care, appropriate and timely discussions with local providers and the patient are crucial in deciding if post-acute care will take place at the treating site, the local site (if not the treating site) or as a shared care arrangement.

Communication

The lead clinician's responsibilities include:

- explaining the treatment summary and follow-up care plan to the patient and/or carer
- informing the patient and/or carer about secondary prevention and healthy living
- discussing the follow-up care plan with the patient's primary healthcare provider.

Supportive care

Other needs that may arise include:

- physical and daily living:
  - support for managing long-term treatment effects and compromised immunity
  - access to physical rehabilitation, occupational therapy, lymphoedema and exercise programs
- healthcare access:
  - transportation assistance for follow-up appointments
  - improved access to specialised survivorship care resources
  - better coordination with healthcare teams
- financial and employment support:
  - financial navigation services tailored to rural and remote circumstances
  - support for return-to-work transitions, particularly given limited rural and remote job markets and that some people are self-employed
  - assistance with disability benefits applications
- psychosocial support:
  - access to mental health services and support groups
  - encouraging patients to identify and coordinate their informal support networks
  - information about self-management strategies
  - support for managing changes in family and social relationships.

Checklist

- ❑ Patient referred to support services (such as the Cancer Council or relevant cancer-specific non-government organisations) as required
- ❑ Patient-reported outcome measures recorded

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 6: Managing recurrent, residual or metastatic disease

Detection

Most residual or recurrent disease will be detected via routine follow-up or by the patient presenting with symptoms. If a patient's cancer has returned, the primary healthcare provider may provide care under the guidance of the treating cancer specialist team. The patient's primary healthcare provider, oncologist or care coordinator should coordinate this care. Referral back to the original team and other multidisciplinary teams is optimal, specifically to discuss further aspects of care. This may involve different therapeutic and supportive care disciplines than when initially discussed.

Due to the high reliance on primary healthcare providers in rural and remote settings, ensure they are included in MDMs about treatment planning and follow-up care to effectively support this once a person returns home.

Treatment

Evaluate each patient for whether referral to the original multidisciplinary team is appropriate. Treatment will depend on the location and extent of disease, previous management and the patient's preferences. Details for appropriate treatments and optimal timeframes are outlined in each cancer-specific optimal care pathway.

Advance care planning

Advance care planning is important for all patients but especially those with advanced disease. It allows them to plan for their future health and personal care by thinking about their values and preferences. This can guide future treatment if the patient is unable to speak for themselves. Give patients and their support network written information to take home.

Survivorship and palliative care

Survivorship and palliative care should be addressed and offered early. Early referral to palliative care can improve quality of life and referral should be based on need, not prognosis. Where access to a palliative care physician or team is limited, explore tele-nursing to connect patients to a suitable alternative. Rural and remote patients may rely more on social networks rather than close family for hands-on care. Targeted interventions can support informal caregivers.

Communication

The lead clinician and team's responsibilities include explaining the treatment intent, likely outcomes and side effects to the patient and/or carer and the patient's primary healthcare provider.

Other challenges and needs that may arise at this time include:

- limited access to specialist palliative care services, particularly in rural and remote areas
- transportation barriers for accessing treatment and follow-up care, often requiring long-distance travel
- need for coordinated care between local healthcare providers and urban treatment centres
- rapid turnover of primary healthcare providers in rural and remote areas, affecting continuity of care
- financial burden from travel costs and accommodation when accessing distant cancer specialist services
- challenges accessing timely symptom management support, particularly acute symptoms
- limited access to psychosocial support services and support groups in rural and remote communities
- need for enhanced communication between rural primary care providers and urban specialist teams
- greater reliance on family caregivers who may experience higher burden due to limited formal support services.

Checklist

- ❑ Treatment intent, likely outcomes and side effects explained to the patient and/or carer and the patient's primary healthcare provider
- ❑ Supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
- ❑ Patient referred to support services (such as the Cancer Council or relevant cancer-specific non-government organisations) as required
- ❑ Advance care planning discussed with the patient and/or carer
- ❑ Patient referred to palliative care if appropriate
- ❑ Routine follow-up visits scheduled

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 7: End-of-life care

Palliative care

Consider a referral to palliative care. Referrals should be made when treatment with curative intent is no longer an option, but before treatment ends. Ensure an advance care plan is in place.

Rural and remote patients face substantial geographic barriers to accessing palliative care services. Offer palliative support more broadly through symptom management if no palliative service is available.

Potential solutions to overcoming access barriers for patients include:

- developing integrated care models linking rural and remote and metropolitan services
- using telehealth for cancer specialist consultations
- strengthening partnerships between local healthcare providers and palliative care services.

In urban areas, end-of-life care is often delivered by a multidisciplinary team. But in rural and remote areas, primary healthcare providers and generalist health professionals often support this care. Share the responsibility for initiating the discussion among the treating team. End-of-life and palliative care services may be better known to the clinician providing services closest to the patient's home, highlighting the need for effective communication between treating clinicians. It's important to use culturally sensitive approaches and consider alternative language, such as 'comfort care', when discussing palliative care.

As voluntary assisted dying (VAD) is legislated by state and territory governments, it is essential to know the law and rules around this choice in the state or territory where the patient lives.

Targeted initiatives have been implemented to improve access to VAD. While progress has been made in providing end-of-life care to rural and remote cancer patients, there are still disparities in access and service availability compared with metropolitan areas.

Communication

The lead clinician's responsibilities include:

- being open about the prognosis and discussing palliative care options with the patient early
- establishing transition plans to ensure the patient's needs and goals are considered in the appropriate environment
- promoting patient education and agency in decision-making
- proactive communication with the patient's primary healthcare provider to inform of changes in medication regimen or of ending active treatment
- communication to inform the treatment team of a death of a patient.

Checklist

- ❑ Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as needed
- ❑ Patient referred to support services (such as the Cancer Council or relevant cancer-specific non-government organisations) as required
- ❑ Patient referred to palliative care
- ❑ Advance care directive in place

Visit our guides to best cancer care webpage <www.cancercareguides.org.au> for consumer guides. Visit our OCP webpage <www.cancer.org.au/OCP> for the optimal care pathway and instructions on how to import these guides into your GP software.

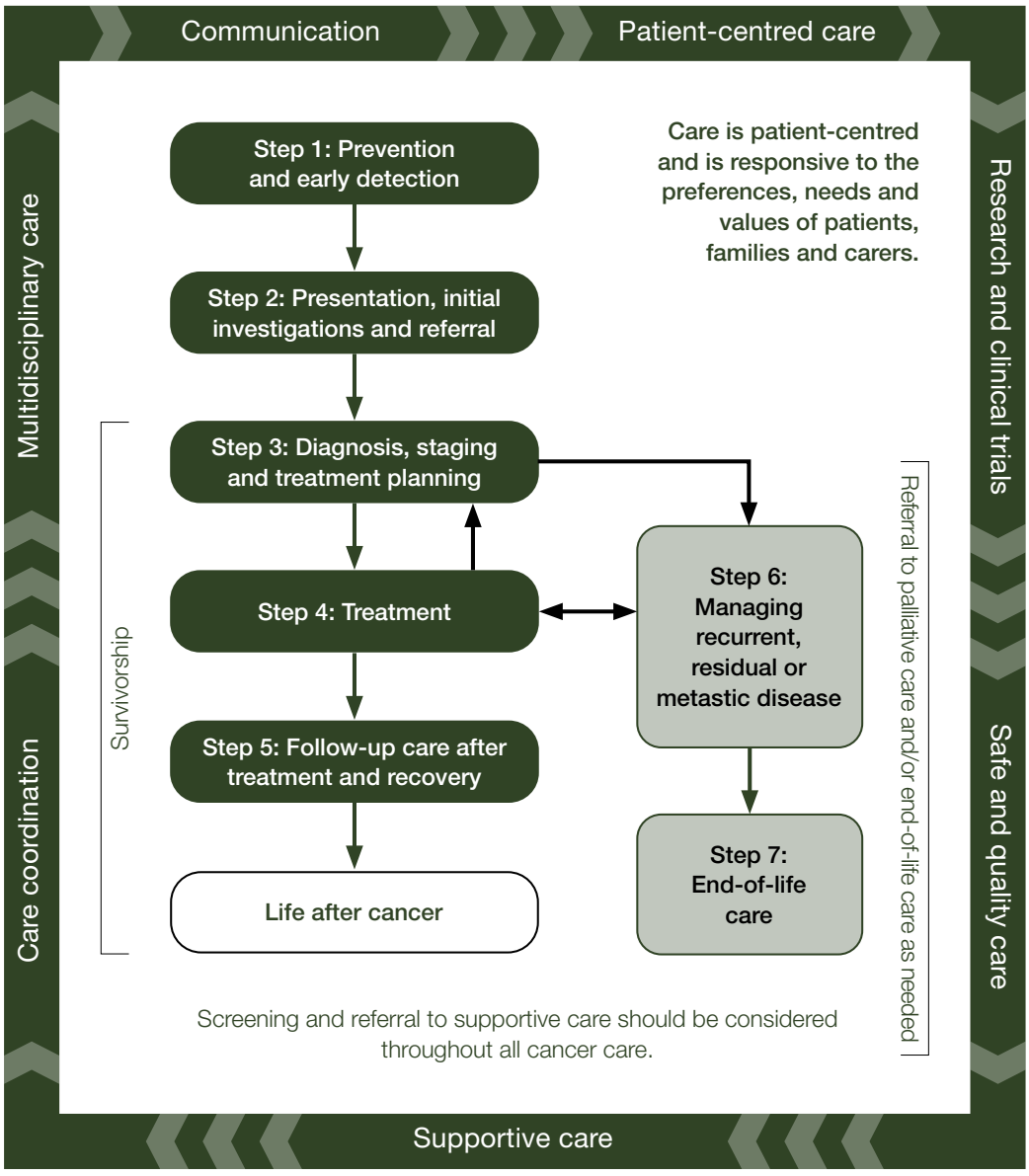
Intent of the optimal care pathways

Optimal care pathways map 7 key steps in cancer care. Each of these steps outlines nationally agreed best practice for the best level of care. While the 7 steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (e.g. the type of cancer, when, where and how the cancer is diagnosed, prognosis, management, the patient's decisions and their physiological response to treatment).

The principles underpinning optimal care pathways always put patients at the centre of care throughout their experience and prompt the healthcare system to deliver coordinated care.

The optimal care pathways do not constitute medical advice or replace clinical judgement, and they refer to clinical guidelines and other resources where appropriate.

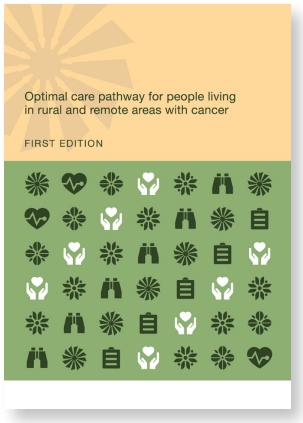
Figure 1: The optimal care pathway



Optimal care pathway resources

There are 3 resources for each pathway: an optimal care pathway, a quick reference guide for health professionals and a guide to best cancer care for patients, carers and families.

Optimal care pathways



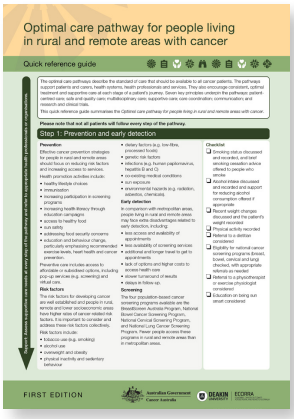
This optimal care pathway is designed for **health professionals and health services**. However, patients and carers may find useful information in this version to help understand the processes their treating health professionals are following.

This resource aims to:

- assist health professionals to provide optimal care and support to patients with cancer, their families and carers
- provide optimal timeframes for delivering evidence-based care
- emphasise the importance of communication and collaboration between health providers and people affected by cancer
- assist and inform new health professionals or trainees who are entering the cancer care workforce
- provide value to health systems to identify gaps in current cancer services, bring about quality improvement initiatives and improve how services are planned and coordinated. Adherence to the pathways should be measured wherever possible.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways.

Quick reference guides



The quick reference guides are for **health professionals and health services**. They provide a summary of each optimal care pathway for health professionals and patients.

The quick reference guides include:

- optimal timeframes within which tests or procedures should be completed
- checklists with indicators related to recommendations in the optimal care pathway.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the quick reference guide for this optimal care pathway.

Guides to best cancer care

The guides to best cancer care are **consumer** resources that help patients understand the optimal cancer care that should be provided at each step. Carers, family and friends may also find the guides helpful.

The guides to best cancer care:

- include optimal timeframes within which tests or procedures should be completed
- include prompt questions to support patients to understand what might happen at each step of their cancer journey and to consider what questions to ask
- provide information to help patients and carers communicate with health professionals are available in 10 languages.

Visit the Cancer Council's website <www.cancercareguides.org.au> to view the guides to best cancer care.

Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* provides a tool to help reduce disparities and improve outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer. This resource can be used in conjunction with the optimal care pathway for each cancer type.

Visit the Cancer Australia website <https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-health> to view the optimal care pathway for Aboriginal and Torres Strait Islander people.

Context

The purpose of the *Optimal care pathway for people living in rural and remote areas with cancer* is to enhance the current best practice information found in the cancer-specific optimal care pathways to facilitate safe, equitable and high-quality care for people in rural and remote areas of Australia.

The *Australian Cancer Plan* <www.australiancancerplan.gov.au> is a strategic document that maps out key focus areas to improve cancer outcomes for all Australians. It identifies people living in rural and remote areas with cancer as one of 10 priority population groups in line with the *National Optimal Care Pathways Framework* <www.canceraustralia.gov.au/national-optimal-care-pathways-framework>. This is due to the unique challenges they face in accessing cancer care. These challenges contribute to disparities in cancer outcomes compared with people who live in metropolitan areas.[1]

Disparities in health care, including the availability of health professionals, accessibility of services and timeliness of care, are factors often associated with rural and remote communities. Defining rural and remote Australia is complex. In Australia, various geographical classification systems are used to define locations as rural and remote using census population data. The Australian Bureau of Statistics' Remoteness Areas classification system <https://www.abs.gov.au/statistics/standards/australian-statistical-geography-standard-asgs-edition-3/jul2021-jun2026/remoteness-structure/remoteness-areas> is widely applied in policy and practice. However, no single agreed definition captures the full diversity of rural and remote experiences.[2]

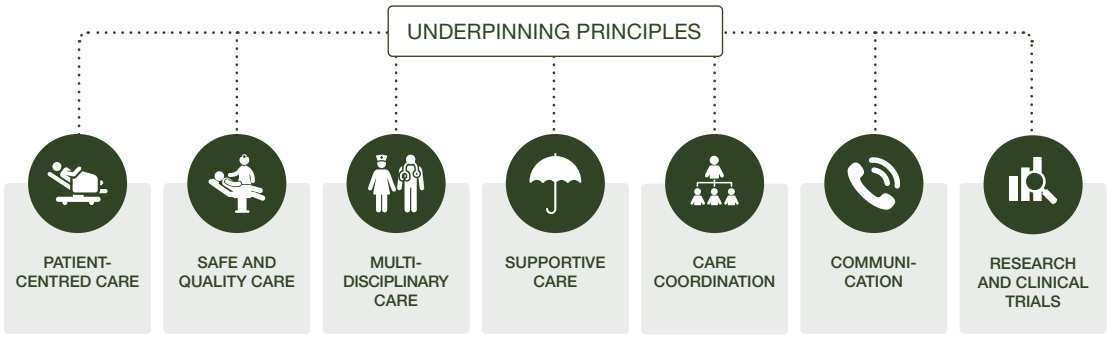
This optimal care pathway acknowledges the variability in challenges across different regions and aims to reflect the diverse experiences of people within these communities. While many challenges are heightened for those living in small, isolated areas, similar issues can also affect people in larger regional towns. Designed to be flexible and adaptable, this pathway considers contextual factors such as the need to travel long distances, socioeconomic barriers and limited access to specialised services, ensuring relevance across a broad range of settings and circumstances. Importantly, these contextual factors have been considered throughout the patient experience.

The nature of Australia's geographical landscape creates fundamental barriers to accessing health care across the country. While this may occasionally be true for metropolitan areas, it is especially relevant to rural and remote communities, hence the focus of this optimal care pathway. Clinicians can use the pathway as an informational resource and tool to facilitate discussion and collaboration between health professionals and people affected by cancer from rural and remote areas. From a policy and research perspective, the pathway can be used to identify gaps in current cancer services and to inform quality improvement initiatives across all aspects of the care pathway. Ultimately, this pathway supports the collective ambition of achieving equitable cancer care for all Australians, no matter where they live.

Principles of the optimal care pathway

The seven principles of care define appropriate and supportive cancer care that is the right of all patients and the right of those caring for and connected with them.

Figure 2: The 7 principles underpinning the optimal care pathway



Principle 1: Patient-centred care

Patient-centred care informs and involves patients in their care and respects and responds to the preferences, needs and values of patients, families and carers.

A patient-centred focus increases the experience and satisfaction of patients, their families and carers, and staff, as well as safety and cost-effectiveness.[3]

Patient-centred care means:

- patients are informed and involved in decisions about their cancer and the treatment, post-treatment and recovery program ahead
- patients, their families and carers are provided with access to appropriate and accessible health information
- respect for the cultural and religious beliefs of patients and their families is demonstrated when discussing the diagnosis of cancer
- active communication is used to engage patients, their families and carers in the care process – an essential step for patients to be informed
- care processes are mutually beneficial for patients and providers
- special needs are addressed – for example, the needs of people with disabilities or mental health issues.

Informed choice and consent

An informed patient has greater confidence and competence to manage their cancer journey.

Health professionals are responsible for enabling patients to make informed choices according to their preferences, needs and values. Patients should be provided with:

- individualised and timely information and guidance about their treatment
- details of their care, including the advantages and disadvantages of each treatment, the associated potential side effects, the likely outcomes on their performance status (how well a patient is able to carry out activities of daily life) and subsequently their quality of life and any financial implications, at each stage of the pathway.[4]

Health professionals have a legal responsibility to obtain consent for all procedures from either the patient or their substitute decision-maker if they are not deemed competent.

Referral choices and informed financial consent

Patients have the right to receive the information they need to be able to make an informed decision on where to be referred for treatment.

At the time of referral, the patient's primary healthcare provider should discuss the different options for referral, waiting periods, expertise, whether there are likely to be out-of-pocket costs and the range of services available. This will enable patients to make an informed choice of a cancer specialist and health service. Referral decisions influence the care patients receive along the pathway and the direct and indirect costs they and their carers may incur. Treating cancer specialists and practitioners are responsible for explaining the costs or how to find out the costs of services, tests, supportive care (including allied health) and treatment options upfront to avoid consumers experiencing 'bill shock'. Obtaining informed financial consent and explaining the expected costs is not a one-off activity at the time of referral. It is an ongoing discussion throughout the entire treatment process.

Different referrals have different costs:

- referral to a public hospital, which may involve some costs
- initial referral to a private cancer specialist with associated costs, with the option of ongoing treatment in a public hospital at any time
- referral to a patient's choice of practitioner for immediate and ongoing private hospital management with associated costs
- referral to a treating hospital close to where the patient lives (if appropriate).

Patients should be made aware that even though public hospital health care is 'free' to all Australian citizens and most permanent residents of Australia, there are still associated direct costs such as:

- over-the-counter medication and prescriptions
- allied health appointments
- costs associated with ongoing healthcare visits
- wound dressings
- travel costs (i.e. transport and accommodation)
- parking fees
- tests that are not covered by Medicare.

If a patient is privately insured, some costs will be covered completely or subsidised, but it is important to note that there can be other out-of-pocket costs associated with private health care that are not covered by insurance.

A cancer diagnosis and treatment may affect a patient's or carer's income. This is an indirect cost associated with cancer. The term 'financial toxicity' describes the impact of changed financial circumstances due to cancer and cancer care. It is attributed to increased expenses paid by patients and families, ongoing out-of-pocket costs and payment for unsubsidised services and medicines and reduced income.[5] Social work support is essential to help patients and their families deal with this issue. Patients should be advised not to undergo private care with significant out-of-pocket expenses if financially constrained. Cancer specialists in private practice need to explain costs at the start of each new treatment to acknowledge the cumulative out-of-pocket expenses that patients can incur.

For more information on informed financial consent see Cancer Council's 'Standard for informed financial consent' <https://www.cancer.org.au/health-professionals/resources/informed-financial-consent>.

Financial counselling services can provide advice on dealing with financial difficulties. These services can be accessed publicly (via social workers at hospitals, financial counsellors at neighbourhood houses or rural financial aid), privately or through cancer support services such as local charity groups or social work services.

For practical and financial assistance, patients may consider Cancer Council's financial services <https://www.cancer.org.au/support-and-services/practical-and-financial-assistance>.

Intersectionality

People living in rural and remote Australia are diverse, and many identify as members of other priority population groups as recognised by the *Australian Cancer Plan,* including Aboriginal and Torres Strait Islander people, lesbian, gay, bisexual, transgender, intersex, queer and asexual (LGBTIQA+) community members, people living with a disability and people from culturally and linguistically diverse (CALD) backgrounds. Recognising intersectionality as an important part of person-centred care ensures cancer pathways respond to the complex, unique and overlapping interplay of cultural, social, economic and health factors influencing each individual. This approach helps reduce inequities, improve access and deliver care that is truly tailored to the diverse needs and lived experiences of patients.

Shared care

Shared care between a cancer specialist and primary healthcare providers is delivered in 2 or more settings by 2 or more professionals. The primary healthcare provider is usually a general practitioner (GP) but can include nurses and allied health practitioners. Shared care can be delivered throughout the care pathway, including during treatment, follow-up care, survivorship care and end-of-life care. Aboriginal community-controlled health services, primary healthcare providers and primary care teams play a vital role in delivering ongoing patient-centred care closer to home.

Shared care offers several advantages to patients, including the potential for treatment closer to home and more efficient care with less duplication and greater coordination. Evidence comparing shared care and specialised care indicates equivalence in outcomes including recurrence rate, cancer survival and quality of life.[6] In rural and remote settings, cancer specialists can communicate directly with the patient and the primary healthcare provider.

Telehealth can enable efficient shared care and should be explored for all patients. Patients in some rural or remote locations may access cancer specialists via Medicare Benefit Scheme funded or public hospital telehealth consultations. Shared and multidisciplinary care can be facilitated by specialist nurses with the patient in the room with them, or remotely. Treating primary healthcare providers, cancer specialists and allied health practitioners working in rural or remote locations should be aware of specialist multidisciplinary teams with facilities to reduce the travel burden and costs for patients. Similarly, specialists and health practitioners working in metropolitan areas should consider telehealth for future appointments for patients who live in rural and remote areas.

Principle 2: Safe and quality care

Hospitals and health professionals are responsible for providing safe and quality care.

Health professionals need to have appropriate training and experience to undertake prevention, screening, diagnosis, treatment, supportive care, survivorship and palliative care for cancer. It is particularly important to acknowledge that operating as a health provider in rural and remote areas requires a certain competency level. It is important that clinicians have time allocated to do the necessary training to upskill as required; this includes understanding the appropriate local referral pathways for different cancers. Patients should be referred to an individual practitioner or service with appropriate expertise.

Safe and high-quality care is care provided by appropriately trained and credentialed health professionals who undertake regular quality reviews of their performance, contribute to regular audits of their care and are actively involved in continuing professional development. Hospitals and clinics must have the equipment, staff numbers, policies and procedures in place to support safe and high-quality care for cancer patients. Patients should be offered the safest options for care, which may include using telehealth.[7]

Hospital quality committees should ensure all health care is informed by evidence, and health professionals and health service managers (including executives) have a responsibility to evaluate and monitor their practice. Optimal care pathways provide a framework to help evaluate and monitor practice over time. Services should be routinely collecting relevant minimum datasets to support benchmarking, quality care and service improvement.[8] Hospital committees and health professional peak bodies should be auditing this process.[4,9]

The Australian Council on Health Standards <https://www.achs.org.au/> has created a set of indicators that helps hospitals conform to appropriate standards.

If, for any reason, a patient's quality of care may be impacted by choosing to receive care in a rural and remote location, clear information should be provided to the patient and/or their family/carer so a fully informed decision can be made, weighing up all options about where to receive care.

Patient-reported experience and outcome measures

Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) should be incorporated into routine cancer care.

PREMs are used to obtain patients' views and observations on aspects of healthcare services they have received.[10] Patient experience data is collected for specific services and then relayed to service providers to instigate improvements in patient services.[11,12]

The Australian Hospital Patient Experience Question Set (AHPEQS) is a tool used to assess patient experiences of treatment and care in a private or public hospital. AHPEQS helps to improve the safety and quality of healthcare by allowing organisations to understand the patient's perspective.[10,11]

PROMs measure aspects of a person's health status such as symptoms, quality of life and needs and are collected directly from patients either online, via a smartphone or through paper-based means.

Collecting PROMs, and then instigating an appropriate clinical response, has been shown to prolong survival, reduce health system use and improve patients' quality of life. While there are many sets of PROMs questions that are relevant to any cancer patient, specific questions can be tailored to particular cancer types, populations or different phases of cancer care.

The appropriate questions related to PROMs for rural and remote Australians living with cancer could focus on key domains, including:

- Health-Related Quality of Life (HRQOL) – measured using validated tools like the Short Form Health Survey (SF-36) to capture physical and mental health components[13]
- psychosocial wellbeing with questions about depression and anxiety symptoms, using validated tools like PHQ-8,[14] ESAS-r[15] or the Distress Thermometer[16]
- financial impact – questions about the financial impact of cancer, assessed with relevant screening tools[17] measuring financial toxicity or work-related disruptions[18]
- access to care, including travel time to specialised facilities, cost barriers to care and frequency of medical consultations[19]
- daily life impact, measured through activities of daily living, participation in social and recreational activities and the impact on family and work responsibilities[18]
- healthcare experience, including whether patients feel heard and acknowledged, whether they experience delays with care and the quality of communication with healthcare providers.[18]

Principle 3: Multidisciplinary care

Multidisciplinary care is an integrated team approach that involves all relevant health professionals discussing all relevant treatment options and making joint recommendations about treatment and supportive care plans, considering the personal preferences of patients.

Multidisciplinary care improves patient outcomes. Cancer Australia's 'Principles of multidisciplinary care' provides a flexible definition, allowing services to vary implementation according to cancer type and the service location. The principles stipulate:

- a team approach that involves core disciplines that are integral to providing good care, including general practice, with input from other specialties as required
- communication among team members about treatment planning and plans for follow-up
- access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution
- care delivery in accordance with nationally agreed standards and evidence-based practice
- patient involvement in decisions about their care.[20]

In addition to these principles, treatment teams should consider clinical trial participation for all eligible patients.

Multidisciplinary meetings, often called MDMs, should be based on the principles outlined above.

Key components of multidisciplinary care for rural and remote Australians living with cancer include:

- specialised roles that provide essential coordination, information and psychosocial support while facilitating communication between patients and the healthcare team[21]
- videoconferencing capabilities for MDMs, with careful attention to meeting format and structure to ensure effective case discussions and treatment planning[22]
- established systems and protocols for care coordination between metropolitan cancer specialists, cancer specialists in regional referral centres and rural healthcare providers, with clear communication pathways and referral protocols[23]
- access to allied health services and support, recognising that rural patients currently face significant barriers to using these essential services compared with metropolitan patients[24]
- formalised connections between primary healthcare providers, local health services, community nurses, Aboriginal health workers and cancer specialists to ensure continuous care and proactive symptom management
- ensuring MDMs have flexible service models to be able to include mobile clinics, visiting cancer specialists and outreach services that bring care directly to remote communities and address where support is required

- engagement with telehealth models that incorporate nursing and allied health to support the delivery of safe cancer care[25]
- given the dependency of rural and regional patients on their primary healthcare providers (including nurse practitioners) for support, they play a larger role in these patients' journeys, assisting with coordination, communication, advocacy and local clinical support. Effective communication within multidisciplinary teams is important, as is communication between these teams and primary care, Aboriginal community-controlled health organisations (ACCHOs) and other local healthcare providers.

For more information on the principles of multidisciplinary care and the benefits of adopting a multidisciplinary approach, refer to Cancer Australia's 'Principles of multidisciplinary care' <https://www.canceraustralia.gov.au/clinicians-hub/multidisciplinary-care/all-about-multidisciplinary-care/principles-multidisciplinary-care>.

Principle 4: Supportive care

Supportive care is a vital part of any cancer care program, through treatment and beyond, and involves counselling to support people to understand and adapt to the medical, psychological, familial and reproductive implications of their diagnosis, especially if there is a genetic component. Supportive care deals with issues that emerge for patients, families and carers from the effects of the cancer diagnosis and its treatment. It is made up of all the services, information and resources patients may need to meet their physical, psychological, social, information and spiritual needs from the time of diagnosis.

Supportive care may be 'patient-defined' and based on unmet needs. It is a core component of evidence-based clinical care, and its benefits are well established. All cancer patients and their carers should be formally supported and have access to understandable, relevant information about the medical, practical and emotional aspects of the cancer and its treatment.[26] The wishes and needs of the patient, their family and their carers should determine the level of support provided. Supportive care is a standard or routine aspect of cancer care, and the treatment team should make patients aware of this.

There are significant challenges for cancer patients in rural and remote Australia relating to unmet supportive care needs, which extend to their families and carers. Patients' families are carers who often live in these same areas or travel extensively to provide vital support. These caring responsibilities can profoundly impact a carer's quality of life and create substantial unmet supportive care needs.[27] Carers with poorer mental health, limited social support, those caring for more frail patients and especially those living in rural and remote locations, are at a significantly higher risk of experiencing a greater burden of unmet supportive care needs. They, too, can encounter substantial barriers to accessing the essential support they require.[28] Addressing these specific needs for carers is crucial for a holistic approach to cancer care in rural and remote communities.

Access to emotional support is particularly challenging for people living in rural and remote areas with cancer, making timely screening, information and referral to relevant psychological support critical.

Cancer Mind Care <https://cancermindcare.org.au/> is an online cancer psychology support resource for people living with cancer. More information about community support organisations that provide supportive care is also available at Cancer Council's support service, on 13 11 20.

It's critical to recognise that supportive care should not be time-limited but rather an ongoing part of the cancer pathway, extending beyond the end of active clinical treatment. This is particularly true for addressing the fear of recurrence and the fear of cancer progression, which are distinct but equally impactful concerns for patients. The fear of recurrence, in particular, is not a one-off conversation but requires sustained attention, integrated into both primary care and ongoing follow-up. Patients often feel adrift or 'in no man's land' once clinical treatment concludes, underscoring the critical need for continuous supportive care during this transition and beyond.

For health professionals, supportive care involves:

- regularly screen and assess patients and families for their supportive care needs
- providing patients with access to a range of multidisciplinary support services, groups and therapies designed to assist them to live with cancer and its treatment and optimise recovery
- optimising referral pathways to community support organisations (cancer-related non-government, not-for-profit and charities) that provide services to people living with and beyond cancer, these address many of the care-navigation, psychosocial and information needs of those affected by cancer[29]
- being aware of and delivering culturally appropriate care
- using the Palliative Care Outcomes Collaboration initiative <www.health.gov.au/contacts/pcoc-palliative-care-outcomes-collaboration> to identify and measure the impact of their service delivery.

All members of the multidisciplinary team have a role in providing supportive care along the care pathway, with special attention at transition points.

Supportive care involves routinely and systematically assessing patients to determine their needs. Health professionals can use a variety of validated screening tools for this task (refer to box on page 23). Clinical review and individual assessment are still required to ensure all patient concerns are identified.

More information

Visit the WeCan website <www.wecan.org.au> for information and resources on supportive care.

Validated screening tools

- National Comprehensive Cancer Network Distress Thermometer and Problem Checklist
- Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)
- Concerns About Recurrence Scale – systematically assesses the extent and nature of women's fears about the possibility of breast cancer recurrence.[30]

Other screening tools to assess supportive care needs for cancer patients, with relevance to rural and remote settings, include:

- Supportive Care Needs Survey (SCNS): The SCNS-SF34 (Short Form 34) assesses needs across multiple domains and has been used in telemedicine interventions for rural people living with and beyond cancer.[31] A new brief version, the SCNS-P&C-6, has been developed specifically for caregivers, showing good sensitivity in detecting unmet needs[32]
- Cancer Survivors' Unmet Needs Measure: Used to assess survivorship needs and strength of these needs in rural settings and is particularly effective for evaluating access to local services and financial support needs[33]
- Patient Screening Questions for Supportive Care: Validated measures used to assess psychosocial distress and needs, particularly effective for underserved populations.[34]

The literature indicates that comprehensive needs assessment should cover multiple domains:

- physical and daily living needs
- psychological needs
- support and supportive services
- sexual needs
- health information needs[35]
- cultural needs
- access to care (i.e. need for travel and accommodation)
- financial needs.

These tools are particularly important in rural and remote settings where there may be other barriers to accessing support services and higher levels of unmet needs. The literature emphasises the importance of using validated tools that can capture both the presence and intensity of needs across multiple domains of care.[36]

Key review points

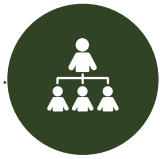
The treatment team should continually assess patients for supportive care needs at every interaction, but particularly at these stages:

- initial presentation or diagnosis (first 3 months)
- the beginning of treatment or a new phase of treatment
- change in prognosis
- if a patient is found to have a germline genetic mutation predisposing to cancer
- end of treatment
- throughout survivorship
- diagnosis of recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care
- other time points based on clinical judgement.

The team also needs to decide whether the patient requires ongoing referral to supportive care services. Access to services can be through general practice–led chronic disease management plans, team care arrangements and mental health plans. Community support services have a role in supportive care to promote early supportive care services reaching the extended family.

Refer to Appendices A, B and C for more information on supportive care and the specific needs of people that may arise.

Principle 5: Care coordination



Care coordination is the responsibility of every professional, both clinical and non-clinical, who works with patients, their families and carers.

Seamless care coordination is essential for patients to successfully navigate the complex health system. Care coordination is a comprehensive approach to achieving continuity of care for patients. It aims to ensure care is delivered in a systematic, connected and timely way that promotes efficiency and reduces the risk of duplication and over-servicing to meet the medical and personal needs of patients.

Care coordination includes:

- proactive and timely communication with patients, their families and carers
- treatment plans, survivorship care plans and/or advance care directives
- coordinated appointments to ensure timely diagnosis, treatment and survivorship care
- appropriate tests and results being available to the treating team so treatment decisions can be made
- medical records being available to all members of the treating team and at scheduled appointments
- translation or interpreter services arranged if the patient/carer is from a non-English-speaking background or has difficulty communicating due to a physical disability
- practical support such as transport, accommodation, advance care planning and financial support
- referral and access to supportive care
- access to clinical trials
- access to telehealth for people in rural and remote areas and for managing vulnerable patients.

Other care coordination considerations for rural and remote Australians living with cancer may include the following:

- Patient navigation services help overcome barriers to accessing health services, particularly for those experiencing socioeconomic disadvantage.[37] The Australian Cancer Nursing and Navigation Program has been introduced to ensure access for all people to high-quality and culturally safe care. The program includes the new Cancer Care Nurse Service delivering cancer care nurses trained with skills and knowledge to work across multiple cancer types, supporting the delivery of tumour-agnostic-based patient navigation services and support[38]
- Specialised nursing roles can provide ongoing telephone support, coordination and psychosocial care between hospital visits[21,39,40]
- Structured multidisciplinary care team meetings can be delivered via videoconference, with careful attention to meeting format to ensure effective case discussions and treatment planning[41]
- Non-government organisations support clinical teams by offering specialist knowledge and consistent care.
- Improved pathways to allied health services and oncology rehabilitation programs after treatment can address the current disparity where remote patients are significantly less likely to access these essential support services. Some support services in rural and remote areas may only be available from private providers, making them financially inaccessible for some people[24]
- Integrating Medicare chronic disease management items recognise that people with cancer living in remote areas are less likely to use team care arrangements and allied health services than those in metropolitan areas[24]
- Identify patients who may not be referred for multidisciplinary care, particularly those with advanced disease, to ensure they receive appropriate specialist input.[42]

Care coordination brings together different health professionals, teams and health services. It also encompasses MDMs, multidisciplinary assessment clinics, supportive care screening and assessment, referral practices, data collection, common protocols, information for patients and individual clinical treatment.

Care coordination should cross the acute and primary care interface and should aim to achieve consistency of care through clear communication, linkages and collaborative integrated care planning.

Effective care coordination is paramount throughout the cancer journey. Electronic health record management systems, such as My Health Record, are invaluable tools for facilitating seamless data collection and information sharing among healthcare providers. These secure online databases support comprehensive care coordination, ensuring all members of the multidisciplinary team have access to critical patient information.

However, the nature of care coordination and supportive care varies significantly across different locations depending on available resources. While a dedicated care coordinator role may not always be defined, nurses are often exceptionally well placed to initiate discussions about support options.

Further advancements in digital health, such as electronic prescriptions (as described in the Australian Digital Health Agency's *National healthcare interoperability plan 2023–28* <https://www.digitalhealth.gov.au/about-us/strategies-and-plans/national-healthcare-interoperability-plan>), will continue to enhance the efficiency and connectivity of cancer care.

Beyond medical and psychological support, legal and financial considerations are also important aspects of comprehensive care. Let patients know about resources such as the Cancer Council's Legal, Workplace and Financial Planning Referral Services <https://www.cancer.org.au/support-and-services/practical-and-financial-assistance/pro-bono-program>, which can assist with matters like wills and powers of attorney.

Intake cancer nurse coordinators – Bendigo Health, Regional Cancer Centre, Victoria

Intake cancer nurse coordinators are the first point of contact for newly referred cancer patients from across the Loddon Mallee region. These expert nurses triage referrals in collaboration with oncologists, coordinate diagnostic workups, undertake comprehensive patient needs assessments and provide tailored information to patients. They also initiate early referrals to other specialists and relevant services, supporting patients and families to navigate their entry into the health system. This role facilitates a coordinated, informed and supported entry to cancer services, with the aim of improving care management across the cancer trajectory from diagnosis through to treatment, in alignment with optimal care pathways. By screening the needs of rural patients prior to service entry, intake cancer nurse coordinators enhance the care coordination and patient experience. For patients required to travel to access services, the role streamlines care and supports coordination with tumour stream nurse coordinators, rural nurse coordinators and metropolitan health services.

Principle 6: Communication

Everyone employed in the healthcare system is responsible for ensuring the communication needs of patients, their families and carers are met.

Good and open communication is a key principle of care for cancer patients. This includes communication between oncology and primary healthcare providers and with patients. Primary healthcare providers should be involved in care from the point of diagnosis, and patients should be encouraged to maintain a relationship with these health professionals through all stages of cancer care. Communication should be regular and timely. For rural and remote patients, effective communication and information sharing between treating and local centres is essential to support patients to navigate and access care, especially when it may be limited closer to home.

Attendance of a family member or carer at clinical appointments is beneficial for many patients, as the family member or carer can provide informational and emotional support. Primary healthcare providers and clinicians should encourage and support the involvement of family members and carers by providing an inclusive and supportive consultation environment.[43] Laidsaar-Powell et al. provide evidence-based guidance on how to support family member or carer involvement in consultations.[43,44]

Every person with cancer will have different communication needs, including cultural and language differences. When anyone involved in treatment communicates with patients, they should be truthful and transparent but aware of cultural and psychological sensitivities. In communicating with patients, healthcare providers should undertake to:

- empower patients to be active in treatment discussions
- use professionally trained interpreters if required – for example, when communicating with people from culturally diverse backgrounds whose primary spoken language is not English and for people with a hearing impairment (visit the Translating and Interpreting Services website <www.tisnational.gov.au> for more information on interpreter and language services)
- use culturally sensitive and appropriate forums of communication for people from culturally diverse backgrounds and Aboriginal and Torres Strait Islander people, as appropriate
- provide appropriate information for people from culturally diverse backgrounds
- provide information on community-based supportive care services and resources to patients and their families and carer
- identify the patient's substitute treatment decision-maker to ensure they are involved in relevant discussions
- ensure patients, their families or their carers have the opportunity to ask questions
- seek consent before conveying information between health professionals or healthcare teams or with family and carers
- be respectful if a patient seeks a second opinion from another health professional

- ensure patients do not have to convey information between areas of care (it is the provider's and healthcare system's responsibility to transfer information between areas of care)
- communicate in plain language (avoiding complex medical terms and jargon)
- ensure information is communicated at a level relevant to the patient's health literacy and that of their families and carers[4]
- use tools, diagrams and aids as appropriate[45]
- ensure the patient is aware of how to access electronic patient information, where appropriate
- allow enough time for communication, especially when conveying complex or sensitive information across the cancer care journey
- check the patient's and/or their family or carer's understanding by asking the patient and/or their family or carer to say in their own words what has been conveyed
- in remote communities, language barriers, limited digital literacy and unstable connectivity can impede understanding. To strengthen communication, resources should be made accessible in low-connectivity areas through downloadable and print-friendly formats.

Communication skills training programs and resources can be found on the following websites:

- Cancer Australia Communication Skills Training <https://www.canceraustralia.gov.au/clinicians-hub/multidisciplinary-care/mdc-for-advanced-disease/communication-and-information>
- Australian Commission on Safety and Quality in Healthcare, Communicating for safety resource portal <https://c4sportal.safetyandquality.gov.au/>
- state and territory Cancer Councils <www.cancer.org.au/about-us/state-and-territory-councils/> for the relevant council
- eviQ <www.education.eviq.org.au>
- VITAL talk <www.vitaltalk.org>.
- Hello my name is <www.hellomynameis.org.uk>
- Intercultural Communication Training <https://www.menzies.edu.au/page/Resources/Intercultural_Communication_Training_information/>.

Telehealth has become an increasingly acceptable alternative to face-to-face consultations. When using telehealth, the team must consider what is best for the patient, including the patient's preferences. This might include providing a face-to-face consultation, when delivering critical diagnosis information, a change in therapy or prescribing intensive treatment. If this is not an option, a video consultation may be offered, and the patient should be encouraged to have a support person with them to assist, whether the appointment is in-person or online.[7] In rural and remote areas, access to in-person healthcare services can be limited due to geographical isolation, workforce shortages and long travel distances. Telehealth helps bridge this gap, offering patients timely access to care without the burden of extensive travel. However, other challenges must be carefully addressed to ensure equitable healthcare delivery, including:

- limited internet connectivity
- broadband and mobile connectivity infrastructure gaps
- lower levels of digital literacy
- socioeconomic factors that limit access
- out-of-pocket costs
- reduced access to local support services.

Principle 7: Research and clinical trials

Research and cancer clinical trials inform evidence-based cancer care by testing new ways to diagnose, treat and manage cancer.

Clinical trials accelerate knowledge gathering and can provide options for cancer patients when other therapies have failed or are yet to be approved. Genomics clinical trials may offer matched therapies not yet available as part of routine care. Results of these clinical trials have informed and advanced cancer care, leading to improved outcomes for many types of cancer.[47] Despite the importance of research and cancer clinical trials, only a small percentage of patients with cancer take part. The literature from high-income countries reports that between 5.4 and 14% of patients with cancer take part in clinical trials.[48,49] Despite the importance of having a diverse range of people participating in cancer clinical trials, some populations are underrepresented in trials, including people with cancer living in rural areas.

As well as potentially benefiting people with cancer now and in the future, conducting clinical research benefits health services by improving adherence to clinical guidelines and evidence-based practices. When physicians take part as trialists, it enhances the institution's research capacity. Importantly, active clinical trial programs are associated with better patient outcomes, suggesting that the rigorous standards of research enhance overall care for all patients, not just those enrolled in trials.[50]

Barriers facing regional, rural and remote Australians

Clinical and structural barriers relate to the availability of clinical trials and the eligibility criteria needed to be met for participation. There is limited availability of clinical trials, which is attributed to geographical barriers, transportation issues, a lack of trials for specific cancers and biomarker-specific eligibility criteria that restrict participation. Also, academic centres (often metropolitan-based) have higher trial participation rates than community settings.[48] Rural areas can also lack the necessary resources and staffing to support trial participation.[51]

Rural health services may experience insufficient research infrastructure, fewer cancer specialists and reduced access to novel therapies.[52] These barriers contribute to reduced access to potentially beneficial experimental treatments and limit the representation of rural patients in clinical research aimed at advancing cancer care.

Physician-related barriers focus on the physician's ability and capacity to discuss clinical trial opportunities with their patients.[53] People with cancer living in rural areas have been described as being less likely to be asked to take part in a cancer clinical trial or to donate biospecimens.[54–56]

It is reported that at least half of the patients who were offered a cancer clinical trial participated, which highlights the willingness of people to take part. However, this challenges the commonly quoted participation rate of 5%, emphasising the significant barriers that prevent most patients from having the opportunity to take part.[57]

Despite these challenges, innovative approaches are emerging as potential solutions to bridge the gap between rural patients and access to clinical trials. Key initiatives that increase participation include establishing clinical trial networks, tele-trials and using a culturally appropriate patient navigator.

Tele-trials

Tele-trials represent a promising solution to address significant disparities in clinical trial access for rural and remote Australians living with cancer. The Australasian Tele-trial Model[58] supported by the Australian Tele-trial Program[59] across 6 states and territories, was specifically developed to bring clinical trials 'closer to home' by using telehealth technology to facilitate remote monitoring and consultations between rural sites and major centres. This approach provides opportunities for GP-led patient monitoring, enabling patients to receive care closer to home while maintaining access to innovative treatments.[60] It helps overcome traditional geographical barriers that have historically excluded rural patients from taking part in clinical trials. Tele-trials are well accepted by regional and rural people.[61]

The sustainability of tele-trials requires addressing several challenges, including investments in infrastructure, workforce training and executive support within rural health services.[58] The literature suggests that a multifaceted strategy incorporating both technological and structural changes – including remote monitoring, decentralised trial designs such as tele-trials and hub-and-spoke networks linking academic and rural centres – will be essential to improve rural patient access to cancer clinical trials and mitigate existing disparities.[62–64]

Clinical trial networks

Clinical trial networks expand access to trials by increasing the number of available trials and participating centres, allowing rural cancer patients to receive care closer to their communities. Establishing a clinical trial network requires financial investment for infrastructure development and dedicated staffing. Considerations include evaluating the return on this investment and ensuring the long-term viability of these initiatives. Also, existing programs must work together to maintain sustainability, avoid redundant efforts and optimise patient outcomes.

Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. Search for a trial <www.australiancancertrials.gov.au> via its website and, for more information, visit the VCCC Alliance Clinical Trial Resource Hub <https://vcccalliance.org.au/research/clinical-trial-innovations/clinical-trial-resource-hub>.

Education and training

Research and clinical trials provide an opportunity to educate health professionals who are in training. Cancer centres may be affiliated with teaching hospitals, universities or research groups to promote higher education or to develop the academic workforce, leading to more sustainable practice. All specialists should be encouraged to take up and retain active membership to professional societies and organisations that can assist with professional development opportunities.

Delivering optimal care for people living in rural and remote areas – further considerations

This section provides more information and guidance about unique concepts in rural and remote cancer care.

Tele-oncology

Tele-oncology is the delivery of telemedicine for cancer care, including a variety of medical models to provide services. These include:

- face-to-face outreach visits complemented by tele-oncology for consultations and supervision of chemotherapy administration
- tele-oncology for consultation and supervision of oral medications
- replacement of face-to-face models with tele-oncology for consultations
- case discussions in MDMs supported with teleoncology.[65]

Tele-oncology plays a crucial role in addressing cancer care disparities for rural patients by improving access to specialised care, reducing travel burdens and maintaining patient satisfaction. This is particularly relevant for rural patients, who often have limited access to oncology specialists.[66]

Telehealth can effectively reduce geographical barriers to cancer care[67] and increase access to specialised oncology for patients in underserved areas.[68] Studies have shown that tele-oncology outcomes are comparable to in-person care, with no significant differences in survival rates, treatment-related toxicities or hospitalisations.[69] High patient satisfaction has also been reported, with a mean satisfaction score of 90.5% for telehealth gynaecological oncology consultations.[69] Data from the United States indicates that 52% of tele-oncology patients are from rural areas, highlighting its significance for these populations.[66] Critical access hospitals in that country have increasingly adopted tele-oncology, with 28% involving non-local oncologists through telemedicine.[70]

Tele-oncology can also strengthen existing rural health system through increasing capability or resources and professionals across rural health services. Other means include cost-effectiveness, improvements in wait times and rural service capability.[71]

Despite these advantages, challenges remain, including technical issues, concerns about patient–provider communication quality[72] and variations in patient comfort and digital literacy.[73] The COVID-19 pandemic has accelerated the adoption of tele-oncology, proving its viability as an alternative to in-person care.[74]

When planning a consultation with a patient, consider whether the consultation is appropriate for telehealth and how the patient could be supported to attend via telehealth.

To fully realise the potential of tele-oncology, continued investment in telehealth infrastructure is needed, along with efforts to address technical and communication barriers and developing personalised approaches to remote care. This might include centralised, purpose-built and dedicated areas with community hubs, such as at a local pharmacy with reliable internet connectivity to support tele-oncology access. Ensuring equitable access across different patient populations will be important for overcoming healthcare disparities. Overall, tele-oncology offers a promising solution for delivering cancer care to rural patients while maintaining high-quality care and patient satisfaction.

The Townsville Teleoncology Network – Townsville Hospital and Health Service, Queensland

The Townsville Teleoncology Network enables rural and remote cancer patients to access specialist cancer care via telehealth. This program aims to improve equity of access to specialist oncology services to patients in rural and remote areas through delivering services in patients' community with no compromise in quality or safety. This model creates a networked cancer care system and builds rural site capabilities by partnering with local managers, doctors, nurses, administrative support officers, health workers, pharmacists and other allied health professionals. Beginning with consultative services in 2007, the network now delivers chemotherapy and other systemic therapies at regional and rural sites using the Queensland Remote Supervision model and clinical trials using the Australasian Teletrial Model. Over the course of the program, there has been consistent and overwhelming support for the benefit to patients and health professionals of providing oncology care, including clinical trials, close to home for those in rural and remote areas. There has also been a positive impact on care for Aboriginal and Torres Strait Islander people for whom receipt of treatment in communities is of cultural importance. The models of care, which were initially implemented in North Queensland, have now been adopted statewide, nationally and internationally.

Patient-assisted travel schemes

Patient-assisted travel schemes (PATs) are an important element of providing equitable access to essential health services for people in rural and remote Australia. The schemes provide partial subsidies to cover the cost of attending cancer specialist medical appointments. Schemes are managed at the state and territory level, and eligibility criteria and subsidy rates can vary between jurisdictions. The published literature on the schemes is limited, yet the impact of travel and financial costs on cancer treatment choices and adherence is significant. Travel expenses are a critical factor influencing treatment decisions. Financial hardship resulting from travel and related costs poses substantial stress for patients, particularly those with lower incomes.[75] Such financial constraints can lead to reduced treatment adherence, and patients may skip or forgo treatments due to these expenses.[76]

Moreover, socioeconomic disparities exacerbate the challenges facing vulnerable populations, particularly rural residents.[77] Addressing these issues requires potential solutions, such as financial assistance programs, to help mitigate travel costs and improve treatment adherence.[78]

More information about PATs is available from the National Rural Health Alliance <https://www.ruralhealth.org.au/publication/fact-sheet/patient-assisted-travel-schemes-guide/> website and Health Direct <https://www.healthdirect.gov.au/travelling-to-your-healthcare-appointment>. Both of these sites outline the details of the scheme in each state and territory.

Referral for rural and remote health care

System-related factors significantly impact cancer care delivery, with inefficiencies in referral processes and limited access being major challenges.[79] To improve outcomes, a multifaceted, system-level approach is necessary, including better coordination of specialist appointments,[80] streamlined referral pathways,[79] enhanced telehealth services and decentralisation of services where feasible.[81] By implementing these strategies, healthcare systems can work towards reducing diagnostic delays and improving timely access to cancer treatment, particularly for rural and underserved populations.

In some underserved communities, primary care can be fragmented by the lack of resident GPs. While most patients with cancer can access primary care in a timely manner,[82] the lack of longitudinal continuity of the primary healthcare providers reduces the frequency of preventive health checks and adherence to local policies and processes. Shared care with general practice, particularly in surveillance, should be balanced to geographically specific factors such as what is going to be most beneficial to the patient.[83]

While metropolitan areas generally have more streamlined and direct referral pathways, rural systems can face fragmentation and coordination challenges that contribute to diagnostic delays.[84,85] Systemic issues such as limited access to diagnostic tests, extended wait times and the need for multiple facility visits further compound these delays.[85] Also, rural healthcare infrastructure often lacks the capacity to support timely cancer specialist care, forcing patients to travel long distances to access essential services.[84] However, evidence indicates that strengthening structured care networks through multidisciplinary cancer teams, formal links with tertiary centres and greater integration of primary care can enhance system efficiency and improve rural cancer care delivery.[86]

Patient and health providers' confidentiality

Privacy and confidentiality present unique challenges in smaller towns and rural areas compared with more populated regions. The increased likelihood of patients knowing their healthcare providers and vice versa complicates anonymity. While some patients may appreciate the familiarity of knowing their clinicians, it's crucial to acknowledge the complexities this introduces for both parties.

To navigate these challenges, consider the following:

- **respect patient preferences and wishes** – understanding that some patients may prefer not to be treated by someone they know personally and support patients to explore alternative options, where possible
- **consider the practicalities of scheduling** – explore options like adjusting appointment times or using different clinic locations where possible to minimise potential encounters that patients may prefer to avoid.

Furthermore, the presence of locum or visiting health professionals can help mitigate some of these concerns because they are less likely to have pre-existing relationships with local patients. It's vital that both patients and health providers are given the necessary support and guidance in managing the unique aspects of confidentiality in close-knit communities.

Optimal care pathway

Seven steps of the optimal care pathway

Step 1: Prevention and early detection

Step 2: Presentation, initial investigations and referral

Step 3: Diagnosis, staging and treatment planning

Step 4: Treatment

Step 5: Care after initial treatment and recovery

Step 6: Managing recurrent, residual or metastatic disease

Step 7: End-of-life care

The aim of this optimal care pathway is to help guide health professionals and health services in system safety and responsiveness to the unique needs of Australians living in rural and remote areas who are diagnosed with cancer. Patient care does not always occur in a linear process but depends on the situation such as the type of cancer, when and how the cancer is diagnosed, prognosis, management, patient decisions and the patient's physiological response to treatment.

This optimal care pathway is intended to complement the cancer and population-specific pathways, acting as a tool to identify areas for health services and health professionals to improve the quality and safety of care provided to rural and remote Australians. The information presented at each step is also complemented by the preceding sections in this document: principles of care and unique considerations.

To view the full clinical optimal care pathway for each cancer type, visit the Cancer Council website <www.cancer.org.au/OCP>.

Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of cancer among Australians living in rural and remote areas.

Evidence shows that not smoking, avoiding or limiting alcohol intake, eating a healthy diet, maintaining a healthy body weight, being physically active, being sun smart and avoiding exposure to cancer-causing viruses or carcinogens may help reduce cancer risk.[87]

Compared with those in metropolitan areas, rural and remote populations experience:

- higher prevalence of modifiable risk factors, including smoking, alcohol consumption, obesity and low levels of physical activity[88–90]
- lower participation rates in national cancer screening programs (bowel, breast and cervical cancer) due to geographical, logistical and cultural barriers[91–96]
- higher rates of late-stage cancer diagnosis, which is associated with reduced survival outcomes[97,98]
- older age in higher proportions, with a greater number of people aged 65 years or older[99]
- lower educational attainment, which influences the incidence of cancer and the demand for cancer services[100]
- greater socioeconomic disadvantage due to the lower educational attainment, reducing employment and income opportunities.[101]

Improving access to preventive health care and increasing participation in cancer screening programs are important for improving cancer outcomes among Australians living in rural and remote areas.

1.1 Prevention

Effective cancer prevention strategies for people in rural and remote areas should focus on reducing modifiable risk factors and increasing access to preventive services.

Delivering preventive care and health promotion activities should focus on healthy lifestyle, immunisation and increasing participation in rural and remote population screening. Preventive care in rural and remote areas should include access to affordable or subsidised options, including pop-up services and virtual care. Also, access to healthy food options, addressing food security concerns and funding programs focusing on education and behaviour change can support engagement in preventive behaviours. It is important to increase health literacy through tailored education and awareness campaigns. This might be through community groups, sporting groups and events such as field days as an opportunity to partner with local residents on health promotion initiatives and cancer prevention.

1.2 Risk factors

Factors that increase the risk of developing cancer are well recognised. These risk factors include:

- tobacco use (e.g. smoking)
- alcohol use
- overweight and obesity
- physical inactivity and sedentary behaviour
- dietary factors (such as low-fibre, processed foods)
- genetic factors
- infections (such as human papillomavirus, hepatitis B and C)
- comorbidities
- sun exposure
- environmental hazards (e.g. radiation, asbestos, chemicals).

Recent spatial analysis has highlighted significant disparities in health behaviours across Australia, revealing that people in remote and lower socioeconomic areas have a higher prevalence of cancer-related risk factors, including smoking, poor quality diet, physical inactivity, environmental hazards (i.e. sun exposure) and excessive alcohol consumption.[102]

There is an importance of addressing multiple risk factors simultaneously in rural and remote communities, with particular attention to the social and geographical determinants that contribute to these higher rates of modifiable risk factors.[64]

There is an importance of ensuring that clinicians in rural and remote areas can effectively support people from culturally and linguistically diverse backgrounds. People migrating to Australia often live in rural and remote areas, but local health services may not be resourced to effectively support people who don't speak English at home.[103]

1.3 Risk reduction

Everyone should be encouraged to address and reduce their risk factors, including:

- quitting smoking[104]
- limiting or avoiding alcohol consumption[104]
- maintaining a healthy body weight[104]
- engaging in regular physical activity while limiting prolonged periods of sitting[104]
- eating a balanced diet with more vegetables, fruits[104] and whole grains while minimising red and processed meat intake
- using appropriate personal protective equipment to reduce the risk of exposure to potential carcinogens
- taking part in recommended national cancer screening programs: BreastScreen Australia, the National Cervical Screening Program, the National Lung Cancer Screening Program and the National Bowel Cancer Screening Program

- staying up to date with hepatitis B and human papillomavirus vaccinations[104]
- reducing ultraviolet exposure[104]
- considering risk-reducing medication or surgery if at high risk (e.g. breast or ovarian cancer).

Effective cancer risk reduction in rural and remote Australia requires targeted strategies to address structural inequities such as limited healthcare access, reduced availability of nutritious food and fewer safe and suitable environments for physical activity. Opportunities include:

- expanding smoking and alcohol reduction support programs
- improving accessibility to healthy, affordable food options
- increasing opportunities for physical activity through investment in community infrastructure
- enhancing awareness of cancer prevention.

Also, strengthening vaccination programs, encouraging sun safety and ensuring culturally appropriate healthcare services are essential to reducing cancer risk and improving health outcomes in these communities.

1.4 Early detection

National screening programs that help to detect cancer early include breast, bowel, cervical and lung cancer screening. BreastScreen Australia <https://www.health.gov.au/our-work/breastscreen-australia-program>, the National Bowel Screening Program <https://www.health.gov.au/our-work/national-bowel-cancer-screening-program>, and the National Cervical Screening Program <https://www.health.gov.au/our-work/national-cervical-screening-program> are established population-based programs that support early screening pathways for eligible populations. In the established screening programs (breast, bowel and cervical cancer), people living in remote areas experience lower participation rates, with the lowest rates observed in very remote areas.[105-107] The National Lung Cancer Screening Program <https://www.health.gov.au/our-work/nlcsp> is particularly relevant to remote areas, where the incidence of lung cancer is highest.[108] The program began in July 2025 using existing public and private low-dose CT scan infrastructure. Mobile lung cancer screening services will be provided as part of the program to address limited access to CT services in rural and remote communities.

In comparison with metropolitan areas, people living in rural and remote areas may face systemic disadvantages related to early detection due to less availability of appointments, less frequency of screening being available, higher costs, slower turnaround of results and, as a result, a delay in follow-up. It is important for services to continue to advocate for screening programs to be extended to rural and remote areas and for those services to be well promoted and culturally safe. Screening program promotion should also include information about the cost of the service, particularly noting that all 4 screening programs are free of charge. Patient-assisted travel schemes may help eligible patients in rural and remote Australia with some travel and accommodation costs for specialist appointments; however, eligibility for cancer screening-related travel varies by state and territory and should be checked with the relevant jurisdictional scheme. Refer to p34 for information on patient-assisted travel schemes.

Major barriers to screening participation for rural and remote Australians include:

- longer travel distances to screening centres[109]
- limited availability of female providers for breast and cervical screening[110]
- cultural concerns and distrust in healthcare systems among Aboriginal and Torres Strait Islander people
- lack of knowledge and awareness of cancer screening[111,112]
- access to afforable accomodation options in locations where screening takes place
- environmental factors such as flood-prone roads and dangerous routes that require a 4WD vehicle for travel
- health literacy challenges[111,113]
- workforce challenges including primary healthcare provider turnover.

1.4.1 Screening recommendations

People living in rural and remote areas should have equal access to screening programs as their metropolitan counterparts.[92,114] This is especially important for those at higher risk of cancer or with a strong family history of cancer. Strengthening outreach efforts through targeted education, integrating lifestyle/prevention counselling into appointments opportunistically, culturally appropriate community engagement and proactive patient navigation can improve participation rates. This includes clear messaging that promotes early detection to encourage people with symptoms to present to their primary healthcare provider sooner, rather than wait for the next time a mobile screening unit visits their local area. Information about upcoming screening should be promoted early and widely to allow time for people to prepare to attend and support should be provided to allow patients to travel from very remote areas to attend mobile screening units. The local workforce should be provided with access to culturally appropriate information resources to understand and refer patients to appropriate screening.

Expanding mobile screening units, integrating pre-screening and follow-up support via telehealth (including the involvement of a person's primary healthcare provider) and enhancing collaboration between local healthcare providers and tertiary centres are highly important system-level strategies. Also, embedding screening initiatives within existing primary care services, including communication with a person's primary healthcare provider and leveraging digital health solutions, can further reduce barriers, ensuring timely detection and improved cancer outcomes for underserved populations.

Step 2: Presentation, initial investigations and referral

This step outlines the process for the primary healthcare provider to initiate the right investigations and refer to the appropriate cancer specialist in a timely manner. The types of investigations the primary healthcare provider undertakes will depend on many factors, including access to diagnostic tests, the availability of medical cancer specialists and patient preferences.

2.1 Signs and symptoms

The timely presentation and investigation of symptoms or signs of cancer is important to optimise cancer outcomes and experiences of care.

There is evidence that people living in rural and remote areas are more likely to have delays in seeking help and in investigation and referral for symptoms than people in urban areas. The lower levels of availability and access to services (e.g. clinic open hours, availability of primary healthcare providers) contribute as a limiting factor to people seeking care. Also, attitudes and beliefs, such as stoicism, self-reliance, optimism, cultural beliefs, fatalism and lower levels of health literacy, may explain why some rural people delay seeking help.[115–118] Work responsibilities, including farming responsibilities, seasonal or shift work in mining industries, have also been identified as an important reason why some people living in rural areas take longer to seek help for symptoms of cancer.[80] However, other research from Victoria has shown a similar time to presentation for people in rural and urban areas with breast or colorectal cancer and did not find that a 'rural attitude' hindered help-seeking for symptoms of cancer.[119] This highlights that there is variation in experiences across the country.

People living in rural areas should be supported to consult with a healthcare provider for symptoms or signs of cancer (e.g. campaigns that advocate for prompt presentation should consider the unique attitudes, beliefs and work commitments that some communities may experience).

- Culturally appropriate support and information should be provided to Aboriginal and Torres Strait Islander people and culturally and linguistically diverse people.
- Given that there may be more prolonged time to presentation among some people in rural and remote areas, it is all the more important that subsequent steps in the diagnostic pathway be optimised to support prompt investigation, referral and access to cancer specialist services.

Access to primary health care is vital for cancer prevention, risk factor management, early detection and timely assessment of symptoms and signs of cancer. However, Australians in outer regional, remote and very remote areas experience longer wait times to see a GP compared with those in major cities. People in remote and very remote Australia lack access to primary healthcare services within an hour's drive from their home (one way).[120] Research in people with cancer has shown that those in rural areas experience longer wait times for GPs than people in major cities, with some also reporting delayed referral for investigations.[119]

Efforts to reduce time to diagnosis in cancer care need to address a range of patient-related, system-related and organisational barriers[80] such as delayed presentation due to limited healthcare access,[97] poor service coordination,[80] geographical challenges,[97] demographic factors and comorbidities.[81]

2.2 General practitioner assessments

General practitioner examinations and investigations

Prolonged time from presentation to cancer diagnosis is associated with poorer cancer outcomes and negative psychological impacts.[121]

There is evidence that suggests access and system capacity issues, such as long travel distances or wait times, are challenging for patients and can delay GP referral for investigations, although this depends on cancer type. An Australian vignette study of GPs' referral practices for patients with gynaecological cancer symptoms found rural GPs waited longer to refer and had poorer access to specialist gynaecological oncologists than urban GPs.[122] Similarly, in a Victorian study, rural GPs reported longer wait times to access investigations or secondary care for some suspected cancer cases and were less likely to have direct access to colonoscopy than urban GPs.[123] Time from presentation to diagnosis of colorectal cancer is longer for people in rural Victoria (compared with urban areas), likely due to the wait time for investigations, but there was no difference in wait time between women with breast cancer living in rural and urban areas.[124]

Cancer diagnosis often requires multiple appointments, investigations and tests. Coordination of investigations is particularly important for people living outside major cities if these require travel. Returning for multiple visits to a centre can be burdensome, particularly for those not living locally and who may have to arrange accommodation, travel, childcare or work changes in order to attend.

Access to investigations, including cancer diagnostic tests, should be enhanced to support prompt ordering of appropriate investigations. Examples include:

- alternative provider models, such as GP-delivered colonoscopy or self-collected cervical screening tests
- telehealth for some types of investigations (e.g. tele-dermoscopy).

Patients should be supported to attend appointments or undertake investigations if these are required. This should include consideration of the costs, travel requirements, as well as other needs (e.g. work, family). Care should also be well coordinated. If multiple tests are required, these should be delivered on the same day to avoid extra visits for testing.

2.2.1 Timeframe for completing investigations

Timeframes for completing investigations and referral should be informed by the relevant cancer optimal care pathways (if available) and evidence-based guidelines (where they exist). Timelines for this group should still be met, while recognising ways to support timely completion of investigations in rural and remote healthcare settings.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways for each cancer type.

2.3 Initial referral

If the cancer diagnosis is confirmed or the results are inconsistent or indeterminate, the primary healthcare provider must refer the patient to an appropriate cancer specialist to make the diagnosis.

Patients should be provided with the relevant information to make informed decisions about their options, including public or private care, choice of cancer specialist and health service. Primary healthcare providers should make referrals in consultation with the patient after considering the clinical care needed, out-of-pocket cost implications, waiting periods, location and facilities, including discussing the patient's preference for healthcare through the public or the private system.

Referral for suspected or diagnosed cancer should include the following essential information to accurately triage and categorise the level of clinical urgency:

- important psychosocial history and relevant medical history
- family history, current symptoms, medications and allergies
- results of current clinical investigations (imaging and pathology reports)
- results of all prior relevant investigations
- notification if an interpreter service is required.

The referring clinician should:

- establish the patient's preferences for where they would like to be referred, including considering any family, employment, agricultural or business commitments as these work patterns can impact care engagement[80]
- seek to understand the patient's preferences and resources to travel through diagnosis, treatment and follow-up, recognising that travel can be a barrier to engagement with treatment (this is particularly important because rural and remote populations have less access to diagnostic and therapeutic services)[80]
- use available information provided by the local Primary Health Network on the health pathways portal (HealthPathways is a clinical management and referral resource designed for use during consultations; it gives clinicians a single website to access clinical referral pathways and resources)
- refer the patient to the relevant tumour-specific non-government organisation (where applicable)
- consider a referral most appropriate to the patient's diagnosis, keeping in mind:
  - local infrastructure of health services and treatment options, noting that not all health services provide all cancer treatments (e.g. radiotherapy is often accessed at metropolitan and regional health services)
  - need for coordination between primary and cancer specialist care providers[125]
  - where the patient lives and what services are locally available, including access to allied health and coordination of appointments for those who need to travel
  - access to diagnostic investigations and cancer specialist appointments[126]
- availability of care coordinators to help navigate complex systems[126]
- ensure clear communication pathways are established between referring primary healthcare providers and cancer specialist services, including:
  - transferring clinical information in a timely way
  - providing discharge summaries and treatment plans without delay
  - clearly documenting medication regimens[125]
  - ensuring effective communication with the specialist team (including specialist cancer nurse coordinators where applicable), including referrals and follow-ups.

It is acknowledged that guidance about the optimal location for cancer treatment can be lacking and that this decision should be made with the patient, reflecting their preferences. There is evidence that people with some types of cancer may benefit from treatment at high-volume centres where similar cases present. However, for people in rural and remote areas, their local health service may not be considered a high-volume centre (e.g. where a high-volume of similar clinical presentations present) and travel may be required. This needs to be balanced against the challenges of accessing care in rural and remote health settings.[80] Using existing networks and better coordination between primary and cancer specialist care can help facilitate more timely and appropriate referrals.[127]

Many services have standard referral requirements and will reject incomplete referrals, so it is important that referrals comply with all relevant health service criteria. The health service is responsible for ensuring follow-up and providing feedback where referrals are incomplete. The cancer specialist should let the referring clinician know that they have received the referral. The referring clinician is responsible for ensuring the feedback from health services is acted on in a timely manner. In instances when locum GPs are employed, or a clinic has a part-time or transient workforce, primary care clinics should ensure they have governance practices in place to allow for timely acknowledgement of communication from health services and instigation of further care or referral as suggested by them. Written information should be provided to the patient about who they have been referred to and why, the potential wait times and when they should expect to hear back.

The cancer specialist should provide timely communication to the primary healthcare provider about the consultation and should notify the primary healthcare provider if the patient does not attend appointments.

Aboriginal and Torres Strait Islander patients will need a culturally appropriate referral. The involvement of Aboriginal and Torres Strait Islander workforce (e.g. an Aboriginal health liaison) is key in rural and remote areas to ensure culturally appropriate pathway and care. To view the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* and the corresponding quick reference guide, visit the Cancer Australia website <https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-health>. Download the consumer resources – Checking for cancer and Cancer from the Cancer Australia website <https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-people>.

2.3.1 Timeframe for referring to a specialist

Telehealth can significantly improve timely referrals for rural and remote Australians living with cancer in several ways. Video consultations enable cancer specialists to provide rapid assessment and treatment recommendations without requiring long-distance travel.[128] Studies have shown high levels of patient satisfaction with this approach, particularly among rural patients.[129] These patients specifically benefit from reduced travel time and less disruption to their daily activities.[128]

For example, the Townsville Tele-oncology Model showed that implementing telehealth services alongside appropriate staffing resulted in 93% of new patients being seen within one week of referral and all urgent cases being reviewed within 24 hours.[71]

Video-based MDMs have also proven effective, with research showing no significant differences in treatment recommendations between videoconference and in-person formats.[130] However, successful implementation requires adequate infrastructure, trained staff and clear communication protocols between specialist cancer centres and local providers.[131] The integration of telehealth has shown particular promise in reducing unnecessary patient transfers while maintaining high-quality care standards.[132]

2.4 Support and communication

2.4.1 Supportive care

The patient's primary healthcare provider, practice nurse and other health professionals should consider an individualised supportive care assessment where appropriate to identify the needs of an individual, their carer and family. Refer to appropriate support services as required. Refer to the validated screening tools mentioned in Principle 4 'Supportive care'. Care coordination is explored in more detail in the following step.

A number of specific needs may arise for patients at this time:

- assistance for dealing with the emotional distress and/or anger of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems and adjustment difficulties management of physical symptoms
- encouragement and support to increase levels of exercise.[133,134]

Other needs that may arise for rural and remote Australians living with cancer include:

- support in managing travel burden to screening, diagnostic and cancer specialist facilities, particularly for initial investigations in non-metropolitan areas[135]
- help navigating and coordinating complex referral pathways and multiple appointments to minimise travel requirements and associated costs[136]
- support using HealthPathways through GPs via their local Primary Health Network to obtain information on best practice patient pathways in their area
- access to culturally appropriate information about screening processes and investigation pathways[137]

- assistance and training to understand and access telehealth services where available for consultations and support[138]
- help managing emotional barriers specific to rural settings, such as concerns about privacy in small communities and fear of travelling to urban centres[109]
- support coordinating care between local primary healthcare providers and urban cancer specialists during the investigation process[139]
- connection to local support networks and peer support services where available[140]
- financial assistance for other rural-specific costs such as extended travel, accommodation and time away from work[141]
- help accessing resources such as We Can <https://wecan.org.au/>, which is an Australian resource that provides information and support services related to supportive care.

For more information on supportive care and needs that may arise for different population groups, refer to Appendices A, B and C.

2.4.2 Communication with patients, carers and families

The primary healthcare provider is responsible for:

- providing patients with information that clearly describes to whom they are being referred, the reason for referral and the expected timeframes for appointments
- requesting that patients notify them if the cancer specialist has not been in contact within the expected timeframe
- supporting the patient while waiting for the cancer specialist appointment (Cancer Council's Cancer Information and Support Service (13 11 20) assists people affected by cancer with practical, financial and emotional support and helps with navigation of and access to available supportive care services)
- where the opportunity presents for cancer specialists to meet with patients, carers and families online, the option should be provided
- information about support should be shared with families and carers where appropriate.

More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer and for planning subsequent treatment. The guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.

3.1 Specialist diagnostic work-up

The treatment team, after taking a thorough medical history and making a thorough medical examination of the patient, should undertake investigations under the guidance of a cancer specialist.

When extensive travel is required for diagnostic work-up, consider whether this is appropriate for each patient. This should include a conversation with the patient about the travel requirements and whether this is appropriate for them. Also consider the patient's suitability (i.e. fitness) for treatment. Travel to some specialised centres to receive care may be arranged through the relevant state/territory patient-assistance travel scheme <https://www.healthdirect.gov.au/travelling-to-your-healthcare-appointment>.

Rapid Access Lung Lesion Clinic (RALLC): a streamlined referral pathway – Grampians Health, Victoria

The RALLC provides an expedited referral pathway for those with suspected, or with a confirmed diagnosis of, lung cancer. The pathway incorporates a multidisciplinary team that expedites diagnosis and treatment. The RALLC team includes a lung coordinator, medical oncologist, respiratory physician and thoracic surgeon, running a weekly clinic followed by fortnightly thoracic MDMs. A centralised referral pathway and referral criteria is utilised, with referrals triaged by an oncologist. Pre-emptive investigations are organised prior to a patient's first clinic appointment to maximise the relevant clinical information available at the first visit, where consultation with all relevant sub-specialties occurs on the same day. For those who need to travel to access the health services, the RALLC reduces the travel burden by ensuring streamlined and multiple investigations and consultations on the same day. The RALLC is an example of a service delivery model that has been adopted widely to improve timeliness to care.

3.1.1 Timeframe for completing investigations

Timeframes for completing investigations and referral should be informed by the relevant optimal care pathways (if available) and evidence-based guidelines (where they exist). Timelines for this group should still be met, while recognising ways to support timely completion of investigations in rural and remote healthcare settings.

It should be noted that delays are often experienced for genomic, blood and anatomical pathology testing in rural and remote areas. This is related to the turnaround time of results. If multiple tests are required, they should be coordinated to happen on the same days, reducing the number of times a patient needs to travel.

Increasingly, timely decision-making in oncology to choose the right treatment at the right time depends on specialised molecular or genetic testing of tumour tissue to find identify changes in cancer cells that predict treatment response or prognosis. These tests are beyond the standard histology and immunohistochemistry tests and take time to complete. This time could take longer in regional and remote areas, therefore advocacy for a close working relationship between oncologist and pathology labs, either local or networked to specialist laboratories, is crucial for timely care.

3.1.2 Genetic testing (family risk)

Precision oncology and genetic testing in cancer care

Certain pathological subtypes of cancer, or tumour tests such as immunohistochemistry and tumour genetic tests, may suggest an underlying inherited cancer predisposition (germline variant). Genetic testing is offered when the eligibility criteria is met. Testing begins with a diagnostic genetic test on a DNA sample from the person with cancer. If a pathogenic gene variant is found, relatives can undergo predictive genetic testing to determine whether they have inherited the variant.

Where there is evidence of benefit, testing for genomic variants within the tumour (somatic variants) can be appropriate. These variants arise during the development of the tumour, and are not inherited. By performing molecular testing of the tumour, relevant matched treatments and genomic clinical trials can be identified, which may lead to fewer side effects of treatment and improved survival outcomes. This is known as precision oncology.

Personal and family history

Everyone diagnosed with cancer should have a detailed personal and family cancer history recorded. Refer to the relevant guidelines <https://www.eviq.org.au/cancer-genetics/referral-guidelines> to determine whether referral to a familial cancer service is appropriate.

Familial cancer service assessment

A familial cancer service assessment can determine whether genetic testing is appropriate. This process usually involves:

- genetic counselling and informed consent before testing
- a face-to-face meeting and formal consent process, which can reduce uptake, particularly for people in rural and remote areas due to restricted access to genetic counsellors.

In some states and territories, treating teams can offer 'mainstreamed' diagnostic genetic testing, after which referral is made to a familial cancer service if a pathogenic gene variant is identified. These services provide:

- risk management advice
- family risk notification
- predictive genetic testing for relatives.

Telephone and videoconferencing counselling sessions are increasingly being used to allow access, reduce travel time and cost with evidence indicating they are well received by patients, with audiovisual solutions preferred over telephone solutions.[142]

For basic information about cancer in a family, visit the Centre for Genetics Education website <https://www.genetics.edu.au/SitePages/Cancer-genetics-overview.aspx>.

Equity-focused delivery models

To continue to improve access and equity, equity-focused delivery models aim to remove barriers to access through:

- inclusive research participation strategies[143]
- culturally appropriate implementation
- consideration of diverse genetic ancestries.

Funding

Some genetic tests are funded through Medicare via a Medicare Benefits Schedule item number. Depending on personal and family cancer history, state health systems may also fund public sector genetic testing.

3.1.3 Pharmacogenetics

Pharmacogenetics describes how individual genetic differences can lead to differences in the way certain medicines interact with the body. These interactions can affect the effectiveness of medications and any side effects. Applying pharmacogenetics to treatment planning may help patients to be prescribed the most appropriate treatment at the optimal dose from the beginning of treatment.[144]

3.1.4 Molecular testing

Molecular testing determines the genetic variants in a person's cancer that can be targeted using specific treatments. Applying molecular and/or pharmacogenetic testing to inform treatment planning is required for many cancer types to ensure patients are prescribed the most appropriate treatment at the optimal dose.[144]

There are multiple models of care to support molecular and pharmacogenetic testing adoption in rural and remote cancer treatment. Technology-enabled care integration combines multiple digital platforms to create a comprehensive support system for rural cancer care. Remote access to molecular tumour boards via telehealth enables real-time collaboration between rural providers and specialist centres for treatment planning.[145] This can be enhanced by digital health innovations to support personalised treatment approaches.[146]

The success of a multi-level implementation framework requires coordinated action across healthcare provider support and access to expert consultation, patient education on self-management programs and system integration to standardise testing protocols and result interpretation.[145]

Critical factors to support molecular and pharmacogenetic testing adoption in rural and remote cancer treatment include:

- integration with existing healthcare pathways
- clear protocols for testing and interpretation
- sustainable funding models
- quality assurance mechanisms[147,148]

An effective approach is the combination of telehealth infrastructure with standardised protocols while ensuring equitable access across populations. This maintains quality care standards while extending specialised services to remote areas.

3.2 Staging

Staging is a critical element in treatment planning and should be clearly documented and accessible in the patient's medical record.

Details for cancer staging are outlined in each cancer-specific optimal care pathway.

Due to factors mentioned in previous sections of this optimal care pathway (e.g. attitudes of stoicism, optimism, self-reliance and difficulty in accessing services in a timely manner), people living in rural and remote areas can present with symptoms later than their metropolitan counterparts and take longer to be diagnosed (e.g. due to slower investigations/diagnostics).

For those living in rural and remote areas, there is a consistent pattern of more advanced stage at diagnosis across multiple cancer types, though this varies across cancer type and rurality.

Contributing factors to later-stage diagnoses in remote areas include limited access to diagnostic services, distance to treatment facilities, longer wait times for cancer specialist consultations and fewer diagnostic tests performed.[97,149] Addressing these barriers is crucial to reducing the disparities in cancer stage at diagnosis and improving outcomes for people living in rural areas.

More information

Visit the Cancer Institute New South Wales website for information about understanding the stages of cancer <www.cancer.nsw.gov.au/understanding-cancer/stages-of-cancer>.

3.3 Performance status

Patient performance status is a central factor in cancer care and should be clearly documented in the patient's medical record.

Performance status should be measured and recorded using an established scale such as the Karnofsky scale or the Eastern Cooperative Oncology Group scale.

3.4 Treatment planning

3.4.1 Key considerations beyond treatment recommendations

A number of factors should be considered at this stage:

- the patient's overall condition, life expectancy, personal preferences and decision-making capacity
- discussing the multidisciplinary team approach to care with the patient
- appropriate and timely referral to an MDM
- pregnancy and fertility
- support with travel and accommodation
- teleconferencing or videoconferencing, including internet connectivity as required.

Other factors to consider at this stage for rural and remote Australians include geographical distance to treatment facilities, seasonal challenges, the nature of employment, socioeconomic disparities and access to supportive care services, all of which can influence treatment decisions and adherence. Bringing care closer to home is the optimal strategy and supported by peak medical and health professional bodies.[150]

Consider the following factors:

- **Cultural and linguistic considerations:** Ensure culturally safe care, access to interpreters and consideration of cultural practices that may influence care decisions.
- **Psychosocial support and mental health care:** Assess and address psychological distress, social isolation and mental health needs, especially for patients in rural and remote areas.
- **Digital literacy and technology access:** Evaluate whether patients have the skills and infrastructure to engage in telehealth or remote care options.
- **Caregiver support and capacity:** Consider the availability and wellbeing of caregivers, who may play a critical role in supporting the patient's treatment and recovery.

- **Family support when the primary caregiver has to leave home:** Often compliance and commitment to treatment relies on the rest of the family having support when the primary caregiver must travel for treatment and is not able to fulfil their responsibilities. Solving this problem often leads to less stress and better compliance and acceptance of treatment.

For example, distance to radiation treatment centres plays a crucial role in treatment selection and adherence among breast cancer patients. For example, women living more than 80 kilometres from treatment centres are more likely to choose mastectomy rather than breast-conserving surgery.[151] Furthermore, those living farther from facilities are less likely to receive the recommended radiation therapy following breast-conserving surgery.[152]

Seasonal factors also influence treatment decisions for people in rural areas. Studies show that women diagnosed with breast cancer during the winter months are less likely to complete radiation therapy. This is due to specific challenges with accessing treatment centres in certain parts of Australia during different seasons. Also, the interplay between travel time and seasonal variations can complicate treatment adherence.[153]

Patients who encounter distance-related barriers and do not receive guideline-consistent radiation therapy often experience worse overall and breast cancer-specific survival rates.[151] It is important to note that not all cancers are equally affected by distance; for instance, travel time to radiation facilities does not significantly impact treatment decisions for prostate cancer, although seasonal factors and urban/rural status may still play a role.[153]

Addressing these barriers is essential to enhancing treatment selection and outcomes, particularly for priority populations. Working with the local team (including primary healthcare providers, Aboriginal health practitioners and nurse practitioners), using telehealth and being innovative to find tailored local solutions where possible are some strategies being used to overcome the geographical barriers that impact rural and remote people's cancer care.

Treatment planning should include advance care planning and goals-of-care discussions, regardless of prognosis. This is also the time to open communication about the benefits of supportive care and palliative care throughout the process.

3.4.2 Timing for multidisciplinary team planning

The multidisciplinary team should meet to discuss newly diagnosed patients before definitive treatment so that a treatment plan can be recommended and there can be early preparation for the post-treatment phase. The level of discussion may vary, depending on the patient's clinical and supportive care factors. Some patients with non-complex cancers may not be discussed by a multidisciplinary team; instead the team may have treatment plan protocols that will be applied if the patient's case (cancer) meets the criteria. The proposed treatment must be recorded in the patient's medical record and should be recorded in an MDM database where one exists.

Teams may agree on standard treatment protocols for non-complex care, facilitating patient review (by exception) and associated data capture.

Results of all relevant tests and access to images should be available for the MDM. Information about the patient's concerns, preferences and social and cultural circumstances should also be available.

Virtual MDMs help overcome geographical barriers and cancer specialist shortages in rural areas.[154] Virtual MDMs appear to be a viable and largely effective option for rural cancer care delivery. However, careful attention must be paid to maintaining team dynamics, ensuring adequate technical infrastructure (e.g. cloud-based IT systems to enable information sharing) and providing appropriate support and training. A hybrid model may offer the best balance of accessibility and effectiveness.

Virtual MDMs can help address rural healthcare disparities while maintaining acceptable clinical quality. Continued evaluation and refinement of virtual MDM processes will be important as these models evolve.

It is also important to establish other communication channels, outside of regular MDMs, to support rural clinicians in diagnosis, staging and treatment planning. Providing additional channels that allow for flexibility and timely communication supports equitable access to cancer specialist expertise, reduces professional isolation and strengthens integration between metropolitan and rural services.

3.4.3 Responsibilities of the multidisciplinary team

The multidisciplinary team requires administrative support in developing the agenda for the meeting, for collating patient information and to ensure appropriate expertise around the table to create an effective treatment plan for the patient. The MDM has a chair and multiple lead clinicians. Each patient case will be presented by a lead clinician (usually someone who has seen the patient before the MDM). In public hospital settings, the registrar or clinical fellow may take this role. A member of the team records the outcomes of the discussion and treatment plan in the patient history and ensures these details are communicated to the patient's primary healthcare provider. The team should consider the patient's values, beliefs and cultural needs, as well as the unique challenges faced due to the patient's geographical location as appropriate to ensure the treatment plan is in line with these.

Lack of MDMs has been identified as a primary reason for suboptimal cancer care for patients living in rural and remote areas.[155] In rural and remote settings, multidisciplinary teams can enhance the quality of care by facilitating regular discussions, leading to improved treatment outcomes. However, due to limited access to specialised health professionals and resources in rural and remote areas, there is a need to consider telemedicine, referral into centralised or metropolitan MDMs and outreach programs to ensure rural patients benefit from multidisciplinary care.

3.4.4 Members of the multidisciplinary team

The multidisciplinary team consists of doctors, nurses and other allied health professionals with specialised knowledge in the relevant type of cancer. This approach involves collaboration among all relevant health professions, who work together to discuss treatment options and make joint decisions about both treatment and supportive care. This approach to care is widely regarded as best practice for planning treatment and providing care for cancer patients[156] and can increase patient survival.[157] The members of a multidisciplinary team in rural and remote areas may not have specialised knowledge across all cancer types. Local clinicians and professionals may be able to provide advice on support services and options that can reduce barriers to accessing treatment such as transport, accommodation and telehealth. Clinicians should be supported through professional networks with larger cancer services to gain access to the information they need to support their patients locally.

For Australians living in rural and remote areas, the composition of multidisciplinary teams must adapt to local resources and needs. For example, some cancer specialists may take part remotely via telehealth. Also, involving a local primary healthcare provider and care coordinator is valuable to ensure treatment plans are tailored to the specific needs and preferences of the rural or remote patient.

The multidisciplinary team should be composed of the core disciplines that are integral to providing good care. Team membership should reflect both clinical and supportive care aspects of care. Pathology and radiology expertise are essential.

Core members of the multidisciplinary team are expected to attend most MDMs either in person or remotely via virtual mechanisms. Additional expertise or specialist services may be required for some patients. An Aboriginal and Torres Strait Islander cultural expert should be considered for all patients who identify as Aboriginal or Torres Strait Islander. More information about the Aboriginal and Torres Strait Islander pathway can be found on the Cancer Council website <https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/OCP-aboriginal-and-torres-strait-islander-people-cancer-second-edition>.

3.4.5 Responsibilities of individual team members

The primary healthcare provider who made the referral is responsible for the patient until care is passed to another practitioner who is directly involved in planning the patient's care.

The primary healthcare provider may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment, shared follow-up care, post-treatment surveillance, coordination and continuity of care, as well as managing existing health issues and providing information and support to the patient, their family and carer.

A study from Queensland compared the roles of rural and urban GPs in colorectal cancer management.[158] This research showed that rural GPs had greater involvement in their patients' care throughout the illness pathway, particularly in care coordination, follow-up and palliative care. GPs may therefore be particularly important in mediating timely cancer care for rural patients.

A nominated contact person from the multidisciplinary team may be assigned responsibility for coordinating care in this phase. Care coordinators are responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase.[159] The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team and for implementing treatment within the multidisciplinary setting.

Models of shared care between metropolitan cancer specialists and rural primary healthcare providers

Shared care models between metropolitan cancer specialists and rural primary healthcare providers are evolving, driven by technological innovations and the need to address rural healthcare disparities. The literature highlights that successful models prioritise flexibility, communication and patient-centred approaches, which are critical for overcoming challenges such as limited cancer specialist resources[160] and technology access and funding barriers.[161]

Key characteristics of effective shared care models include flexible communication channels, clear care coordination protocols and technology-enabled interactions.[162] Also, mutual training and knowledge exchange among providers are essential for building confidence and enhancing care coordination.[163]

Despite these advancements, challenges remain, including varying provider comfort with remote consultations and complexities related to reimbursement and legal issues.[164] Given the difficulties in maintaining the general practice workforce in some regions, complex care coordination, particularly in lengthy surveillance regimens, may also impose a greater responsibility on individual patients or cancer services. Addressing these barriers will be important for the continued development and implementation of shared care models that effectively support rural patients in accessing high-quality care.

3.5 Research and clinical trials

Rural patients are as interested in taking part in clinical trials as people who live in urban areas, despite varied levels of knowledge about what is available.[165] People with cancer living in rural areas are willing to take part in cancer clinical trials given the opportunity.[166] Therefore, cancer specialists and multidisciplinary teams treating rural patients should be aware of or search for clinical trials that may be suitable for their patients so that these may be discussed. Cancer specialists should be willing to refer appropriate patients to other treating centres to take part in research or clinical trials at any stage of the care pathway and be prepared to discuss the benefits and drawbacks of participating in such trials. Any member of the multidisciplinary team can encourage cross-referral between clinical trial centres.

Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. Search for a trial at the Cancer Australia website <www.australiancancertrials.gov.au>.

Health services should strive to implement policies and procedures that facilitate equitable access to clinical trials for all patients, including those from culturally diverse backgrounds, regional areas and Aboriginal or Torres Strait Islander communities. Also explore opportunities for tele-trials and shared care.

On the other hand, possible ineligibility to take part in a clinical trial should be discussed with the patient; it is important to acknowledge disappointment and offer support in this instance.

Some larger cancer centres are running programs to increase access to trials for people living in rural and remote areas through partnership and collaboration with smaller centres. For more information visit the Cancer Australia website <www.australiancancertrials.gov.au>.

For more information and resource links, refer to Principle 7 'Research and clinical trials'.

3.6 Support and communication

3.6.1 Prehabilitation

Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutrition and psychological strategies to prepare patients for the challenges of cancer treatment such as surgery, systemic therapy and radiation therapy. Team members may include anaesthetists, oncologists, surgeons, haematologists, clinical psychologists, exercise physiologists, physiotherapists and dietitians, among others. Although not all disciplines are available locally, and local multidisciplinary team members may lack specialised knowledge across all cancer areas, clinicians should engage with larger professional networks to ensure patients receive appropriate prehabilitation, including care delivered via telehealth where needed.

Patient performance status is a central factor in cancer care and should be frequently assessed. All patients should be screened for malnutrition using a validated tool, such as the Malnutrition Screening Tool (MST). The lead clinician may refer obese or malnourished patients to a dietitian preoperatively or before other treatments begin.

Patients who currently smoke should be encouraged to stop smoking before receiving treatment. This should include an offer of referral to Quitline in addition to smoking cessation pharmacotherapy if clinically appropriate.

Evidence indicates that patients who respond well to prehabilitation may have fewer complications after treatment. For example, those who were exercising before diagnosis and patients who use prehabilitation before starting treatment may improve their physical or psychological outcomes, or both, and this helps patients to function at a higher level throughout their cancer treatment.[167,168]

For patients with cancer, the multidisciplinary team should consider these specific prehabilitation assessments and interventions for treatment-related complications or major side effects:

- conducting a physical and psychological assessment to establish a baseline function level
- identifying impairments and providing targeted interventions to improve the patient's function level[169]
- reviewing the patient's medication to ensure optimisation and to improve adherence to medicine used for comorbid conditions.

Following completion of primary cancer treatment, rehabilitation programs have considerable potential to enhance physical function.

3.6.2 Fertility preservation and contraception

Cancer and cancer treatment may cause fertility problems. This will depend on the age of the patient, the type of cancer and the treatment received. Infertility can range from difficulty having a child to the inability to have a child. Infertility after treatment may be temporary, lasting months to years, or permanent.[170]

Patients need to be advised about and potentially referred for discussion about fertility preservation before starting treatment and need advice about contraception before, during and after treatment. Patients and their family should be aware of the ongoing costs involved in optimising fertility. Fertility management may apply in both men and women. Fertility preservation options are different for men and women and the need for ongoing contraception applies to both men and women.

The potential for impaired fertility should be discussed and reinforced at different time points as appropriate throughout the diagnosis, treatment, surveillance and survivorship phases of care. These ongoing discussions will enable the patient and, if applicable, the family to make informed decisions. All discussions should be documented in the patient's medical record.

As fertility service providers may be located at some distance from rural, regional and remote patients, early consideration of fertility management should occur with referral to fertility preservation providers following liaison with the multidisciplinary team.

More information

Refer to the Cancer Council website <www.cancervic.org.au/living-with-cancer/common-side-effects/fertility/fertility-overview.html> for more information.

3.6.3 Supportive care

Refer to the validated screening tools mentioned in Principle 4 'Supportive care'.

Intention of supportive care

There is great disparity in access to supportive care across the country. Some rural and remote areas may have more access to supportive care than others. Typically, this depends on the available local workforce. Also, travelling to seek supportive care is not always an option, particularly due to the ongoing nature of the care (i.e. it is not a once-off occurrence). Despite existing patient travel support schemes, accessing the scheme can be challenging and can take months to seek approval. Using the scheme can also be challenging because it only covers approved types of care, meaning some cancer specialist medical visits are covered, others are not, and some jurisdictions allow certain allied health services under specific conditions.

A number of specific challenges and needs may arise for patients at this time:

- assistance for dealing with psychological and emotional distress while adjusting to the diagnosis; treatment phobias; existential concerns; stress; difficulties making treatment decisions; anxiety or depression or both; psychosexual issues such as potential loss of fertility and premature menopause; history of sexual abuse; and interpersonal problems
- management of physical symptoms such as pain and fatigue and treatment-related nausea and vomiting[171,172]
- support for families or carers who are distressed with the patient's cancer diagnosis
- support for families/relatives who may be distressed after learning of a genetically linked cancer diagnosis
- specific spiritual needs that may benefit from the involvement of pastoral/spiritual care
- risk of cancer-related malnutrition, sarcopenia and/or cachexia, all characterised by loss of lean mass and inflammation, should be identified early using a validated nutrition screening tool such as the Malnutrition Screening Tool,[173] followed by a valid diagnostic assessment so that appropriate prevention and treatment can be provided. Note that many patients with a high BMI (obese patients) may also be malnourished.[173,174] For those living in rural and remote areas, the Malnutrition Screening Tool can be administered by carers or can be self-screened when patients are not onsite at a healthcare facility.[175] Those living in rural communities are at greater risk of pre-existing malnutrition compared with their metropolitan counterparts.[176]

Other needs that may arise for rural and remote Australians living with cancer include:

- support managing increased travel distances to access cancer specialist care and staging investigations, particularly for those in non-metropolitan areas[177]
- assistance coordinating multiple appointments and tests to minimise travel burden where possible[178]
- help accessing specialist multidisciplinary care teams because rural patients are less likely to receive cancer specialist consultation[179]
- support with navigating referral pathways between local providers and urban specialist centres[180]
- financial assistance for extended travel and accommodation costs during diagnostic workup[181]
- information about and support accessing telehealth services where available for consultations and care planning[182]
- cultural and language-appropriate education about diagnosis and treatment options[183]
- connection to local support networks and patient navigation services to help coordinate care[184]
- assistance for family members who may need to travel long distances to support patients during diagnosis and treatment planning.[185]

Palliative care may be needed alongside treatment for pain management, but access can be limited due to uneven provision of palliative and end-of-life care across Australia, particularly in rural and remote areas.

For more information on supportive care and needs that may arise for different population groups, refer to Appendices A, B and C.

3.6.4 Communication with patients, carers and families

In discussion with the patient, the lead clinician should undertake the following:

- Establish if the patient has a regular or preferred primary healthcare provider and if the patient does not have one, then encourage them to find one.
- Provide written information appropriate to the health literacy of the patient about the diagnosis and treatment to the patient and carer and refer the patient to the *Guide to best cancer care* (consumer optimal care pathway) for their cancer, as well as to relevant websites and support groups as appropriate.
- Provide a treatment care plan including contact details for the treating team and information on when to call the hospital.
- Discuss a timeframe for diagnosis and treatment with the patient and carer.
- Discuss the benefits of multidisciplinary care and gain the patient's consent before presenting their case at an MDM.

- Refer patients to relevant non-government organisations to provide emotional support, logistical support and information in the diagnostic phase.
- Discuss the accessibility of services, travel requirements, appropriateness of telehealth services and financial assistance that a patient may be entitled to.
- Provide brief advice and refer to Quitline (13 7848) for behavioural intervention if the patient currently smokes (or has recently quit), and prescribe smoking cessation pharmacotherapy, if clinically appropriate.
- Recommend an 'integrated approach' throughout treatment regarding nutrition, exercise and minimal or no alcohol consumption among other considerations.
- Communicate the benefits of continued engagement with primary care during treatment for managing comorbid disease, health promotion, care coordination and holistic care.
- Where appropriate, review fertility needs with the patient and refer for specialist fertility management (including fertility preservation, contraception, management during pregnancy and of future pregnancies).
- Be open to and encourage discussion about the diagnosis, prognosis (if the patient wishes to know) and survivorship and palliative care while clarifying the patient's preferences and needs, personal and cultural beliefs and expectations, and their ability to comprehend the communication.
- Encourage the patient to participate in advance care planning including considering appointing one or more substitute decision-makers and completing an advance care directive to clearly document their treatment preferences. Each state and territory has different terminology and legislation surrounding advance care directives and substitute decision-makers.

3.6.5 Communication with the primary healthcare provider

The lead clinician has these communication responsibilities:

- involving the primary healthcare provider from the point of diagnosis
- ensuring regular and timely communication with the primary healthcare provider about the diagnosis, treatment plan and recommendations from MDMs and inviting them to participate in MDMs (consider using virtual mechanisms)
- supporting the role of general practice both during and after treatment
- discussing shared or team care arrangements with the primary healthcare provider or regional cancer specialists, together with the patient.

More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 4: Treatment

Step 4 describes considerations for optimal treatments for cancer among rural and remote Australians, the training and experience required of the treating clinicians and the health service characteristics required for optimal cancer care. A personalised treatment plan may also be informed by genomic testing. Genomics-informed cancer care can improve the experience of people affected by cancer by optimising treatment response and minimising treatment toxicity.

Details for appropriate treatments and optimal timeframes are outlined in each cancer-specific optimal care pathway.

Treatment decisions for patients living in rural and remote areas should respect patient preferences and logistics relating to travel, time spent away from home, their work and employment, competing commitments and culture. Rural and remote patients should not receive inferior treatment due to their geographical location but consider patient preferences following an informed discussion. It is the responsibility of healthcare providers to explain any expected costs of care and to gain financial informed consent.

All health services must have clinical governance systems that meet the following integral requirements:

- identifying safety and quality measures
- monitoring and reporting on performance and outcomes
- identifying areas for improvement in safety and quality.[4]

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

The treatment intent should be established in a multidisciplinary setting, documented in the patient's medical record and conveyed to the patient and carer as appropriate.

The potential benefits need to be balanced against the morbidity and risks of treatment.

The lead clinician should discuss the advantages and disadvantages of each treatment and associated potential side effects with the patient and their carer or family before treatment consent is obtained and begins so the patient can make an informed decision. Supportive care services specific to the patients' circumstance should also be considered during this decision-making process. Patients should be asked about their use of (current or intended) complementary therapies (refer to Appendix D). Read more on supportive care above in section 3.6.3 'Supportive care'.

Timeframes for starting treatment should be informed by evidence-based guidelines where they exist. The treatment team should recognise that shorter timeframes for appropriate consultations and treatment can promote a better experience for patients.

Initiate advance care planning discussions with patients before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive). Formally involving a palliative care team/service may benefit any patient, so it is important to know and respect each person's preference.

4.2 Treatment options

The geographical distance to treatment facilities may impose significant barriers affecting how quickly treatments can begin for people living in rural and remote areas with cancer. The most prominent challenge is the need for extended travel to larger regional centres and metropolitan areas for accessing diagnostic tests, surgeries, radiation therapy, systemic treatments and follow-up care.[186] Also to be considered is the potential loss of family and community support networks, impacting people's choice to travel for treatment. This is compounded by the logistical complexity of coordinating multiple appointments and travel arrangements.[177] Limited availability of specific diagnostic equipment in rural areas means patients must travel for essential pre-treatment testing, which can delay the start of treatment.[186] Healthcare workforce issues also play a role, with rural areas facing challenges in retaining clinical staff and maintaining adequate staffing levels, which can impact timely access to treatment planning and delivery.[186] Also, rural patients have more limited access to specialist multidisciplinary care teams, potentially delaying treatment decisions and the start of therapy.[179] These barriers are further complicated by the financial stress associated with travel and accommodation costs, along with a lack of knowledge about available support services that could help overcome these geographical challenges.[186]

While these geographical barriers present significant challenges to treatment access and initiation, it is crucial to work with the patient and family to overcome them because timely access to surgery, radiation therapy, systemic therapy (including targeted therapies, immunotherapy and emerging therapies) offers substantial benefits for patient outcomes.

4.2.1 Surgery

People with cancer undergoing surgery typically require comprehensive postoperative care, including wound management, physical rehabilitation and monitoring for complications. Also, rehabilitation services (including physiotherapy, occupational therapy or pain management) may be required for postsurgical recovery. In rural and remote settings, access to postoperative care services must be carefully evaluated and considered during the treatment planning process, including the accessibility and cost of these services.

Health service characteristics

To provide safe and quality care for patients having surgery, health services should have these features:

- critical care support for certain cancer operations
- 24-hour medical staff availability
- 24-hour operating room access and intensive care unit for certain cancer operations
- diagnostic imaging
- pathology
- nuclear medicine imaging for certain cancer operations.

4.2.2 Radiation therapy

Radiation therapy access in rural and remote Australia faces significant challenges. Evidence indicates that people living more than 100 kilometres from a radiation therapy centre are significantly less likely to receive radiation treatment, even when clinically indicated.[187] Distance remains a major barrier, with patients travelling extensive distances to access radiation therapy.[188] This travel burden may lead to emotional stress, financial strain, and separation from loved ones.[189]

Establishing regional radiation therapy centres has improved access and reduced travel times.[188] While regional radiation therapy centres have improved access, a complex interplay of socioeconomic, cultural and health system factors continues to influence rural patients' decision-making for radiation therapy.[190] The availability of radiation oncologists can influence the availability of these services in rural and remote areas.

Rapid access palliative radiation therapy clinics support the streamlined delivery of care, where the consultation, simulation and treatment can occur for palliative radiation treatment. Few of these clinics currently exist in Australia,[191] but they can offer efficient care for patients who have travelled.

Implementation of advanced radiotherapy technology to improve clinical outcomes in rural NSW – Central West Cancer Care Centre, New South Wales

The availability of advanced radiotherapy technology to treat cancer is limited in rural Australia. At Central West Cancer Care Centre, the utilisation rate of intensity-modulated radiotherapy and volumetric modulated arc therapy was significantly lower compared with other NSW public health services. It also lacked facilities for stereotactic ablative body radiotherapy (SABR) treatment. Following multiple quality improvement projects including commissioning of radiotherapy technology and optimisation of quality assurance methods, the access rates to these services improved significantly.[192]

This example emphasises that state-of-the-art treatment can be implemented in rural settings by trained teams with a strong commitment and collaborative approach to implementation. These changes have meant that treatment is completed sooner than conventional radiotherapy because the required dose requires fewer trips to the hospital, patients don't need to travel to a metropolitan centre to have advanced radiotherapy treatment including SABR and patients benefit from improved comfort and equity of access to the best radiotherapy service in the region.

Health service unit characteristics

To provide safe and quality care for patients having radiation therapy, health services should have these features:

- linear accelerator (LINAC) capable of image-guided radiation therapy (IGRT)
- dedicated CT planning
- access to MRI and PET imaging
- automatic record-verify of all radiation treatments delivered
- a treatment planning system
- trained medical physicists, radiation therapists and nurses with radiation therapy experience
- coordination for combined therapy with systemic therapy, especially where facilities are not co-located
- participation in Australian Clinical Dosimetry Service audits
- an incident management system linked with a quality management system.

4.2.3 Systemic therapy

Some patients may benefit from systemic therapy. Delivering systemic cancer therapy in rural and remote areas demonstrates both promising advances and persistent challenges. A significant breakthrough has been successfully implementing tele-oncology and remote systemic therapy services, which have shown comparable clinical outcomes to primary treatment sites.[69] This model has effectively expanded care access while maintaining treatment quality and safety standards.

However, delivering systemic therapy faces several complex challenges. Emergency presentations during treatment are influenced by multiple factors, including limited access to trusted care providers, access to supplies (e.g. blood products), unpredictable treatment responses and broader social determinants of health.[193] To address these challenges, innovative approaches such as home-based treatment strategies combined with telemonitoring have emerged as potential solutions.

Integrating technology has become increasingly important, with electronic PROMs and remote monitoring systems being developed to enable early detection of complications and support patient self-management.[194] However, successfully implementing these systems requires careful consideration of the digital divide and appropriate support programs to ensure equitable access.[195]

Despite these advances, significant infrastructure and coordination challenges persist in some areas. These include distance to treatment centres, limited availability of specialised healthcare providers and the need for coordinated care across multiple providers. Moving forward, the evidence suggests that while remote delivery of systemic therapy is feasible and can produce comparable outcomes to primary sites, success requires robust infrastructure, coordinated care networks and targeted support systems to overcome the unique challenges of rural and remote healthcare delivery.[25,196]

Chemotherapy at home model has gained traction and validation as a model of care in metropolitan areas.[197] It operates under state health regulations, clinical and accreditation guidelines (COSA and ACHS guidelines).[198] It is not yet evaluated in regional and rural areas and this will likely continue to be explored. In the meantime, the guiding principle of safe care as close to home remains.

In a setting where no medical oncologist is locally available (e.g. within some regional or remote areas), some components of less complex therapies may be delivered by a cancer specialist physician, primary healthcare provider or nurse with training and experience that enables credentialing and agreed scope of practice within this area under the direction of a multidisciplinary team. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with a supervising medical oncologist, haematologist or as clinically required.

Health service characteristics

To provide safe and quality care for patients having systemic therapy, health services should have these features:

- a clearly defined path to emergency care and advice after hours
- access to diagnostic pathology including basic haematology and biochemistry, and imaging
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including preparation, waste procedures and spill kits[199]
- guidelines and protocols to deliver treatment safely (including dealing with extravasation of drugs)
- access to information and education on managing acute toxicities
- coordination for combined therapy with radiation therapy, especially where facilities are not co-located
- appropriate molecular pathology access.

Other health service features or considerations to provide safe and quality care in rural and remote Australia include:

- specialist cancer nurses or nurses trained in administering antineoplastic drugs in local hospitals (under the remote supervision of the medical haematology/oncology team)
- adequate facilities to deliver antineoplastic (SACT) drugs safely, where they are being infused
- specialist pharmacists available onsite or via remote models
- access to medication via a pharmacy
- protocols to enable treatments and investigations to be provided in patients' homes
- adequate facilities, accommodation and transport support for patients
- management strategies for human and material resource constraints and their impact on nursing staff
- ongoing evaluation of risks and benefits of care.

4.2.4 Targeted therapies and immunotherapy

Targeted therapies and immunotherapy access in rural and remote settings can present challenges in offering these promising treatment opportunities. Geographical location remains a barrier, with rural patients facing greater difficulties accessing immunotherapy compared with their urban counterparts.[200] These challenges are intensified by socioeconomic factors and insurance status, particularly affecting lower income patients.[201] However, these challenges are being overcome with the timely and effective delivery of oral treatments.

Clinical management in rural settings requires careful coordination between healthcare providers and cancer specialists to manage complex side effects, which becomes particularly challenging when patients are located far from specialty centres.[202] However, emerging solutions such as telehealth services and establishing networks between rural providers and academic centres have shown promise in improving access to expert consultation and support.[203] The proactive development of referral networks, training of local nursing staff and implementation of coordinated care pathways represent potential solutions to improve access and outcomes for rural patients receiving these innovative treatments.

4.2.5 Emerging therapies

The key principle for precision medicine is prompt and clinically oriented communication and coordination with an accredited laboratory and pathologist. Tissue analysis is integral for access to emerging therapies, and as such, tissue specimens should be treated carefully to enable additional histopathological or molecular diagnostic tests in certain scenarios. For rural and remote Australians, this may involve longer transport times for tissue samples, increasing the risk of delays in obtaining critical results. There may also be increased costs associated with emerging therapies because rural and remote health service providers may not be able to absorb costs in the same way that a metropolitan health service can. Ensuring efficient logistics, clear communication between regional and metropolitan laboratories and access to telehealth consultations with pathology specialists can help mitigate these delays. Also, supporting rural healthcare providers with ongoing education and resources for sample collection and handling is essential to ensure equitable access to precision medicine, regardless of geographical location.

4.3 Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness by preventing and relieving suffering through early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems.[204] It is separate from, but complementary to, end-of-life care.

End-of-life care is a specialised area of palliative care focusing on people in the final stages of a life-limiting illness. It aims to improve quality of life through comprehensive physical, emotional, social and spiritual support. This includes symptom management, assistance with daily tasks, psychological and spiritual care and bereavement support for families and carers.[205]

Both palliative and end-of-life care are holistic in nature and address not only physical symptoms but also psychosocial and emotional wellbeing of each person.

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits.[206–208] This is particularly true for cancers with poor prognosis.

For rural and remote Australians, limited local palliative care services and long travel distances to cancer specialist providers can delay access to essential care. Exploring options for telehealth consultations, outreach services and coordination with local healthcare providers can help bridge this gap. In rural and remote areas, some primary healthcare providers will provide palliative care support to patients.

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis. The value of palliative care in improving symptom management and quality of life should be emphasised to patients and their carers.

The 'Dying to Talk' resource may help health professionals when initiating discussions with patients about future care needs (refer to 'More information'). Ensure that carers and families receive information, support and guidance about their role in palliative care.[209]

Patients, with support from their family or carer and treating team, should be encouraged to consider appointing a substitute decision-maker and to complete an advance care directive. Considering the potentially heightened cultural barriers in rural and remote settings is crucial for the successful adoption of palliative care.

Refer to step 6 for a more detailed description of managing patients with recurrent, residual or metastatic disease.

More information

These online resources are useful:

- Advance Care Planning Australia <www.advancecareplanning.org.au>
- Care Search <www.caresearch.com.au/About-Us/Navigating-Our-Website>
- Dying to Talk <www.dyingtotalk.org.au>
- Palliative care resource kit <www.health.gov.au/health-topics/palliative-care>
- Palliative Care Australia (for patients and carers) <www.palliativecare.org.au>.

4.4 Research and clinical trials

The treating team should be aware of potential clinical trials, particularly for emerging treatments and rare, hard-to-treat cancers, for which there may be limited evidence on how the condition is best treated or managed.[210] This may mean identifying clinical trials outside the treating centre. These clinical trial opportunities should be discussed with potential participants so they can consider their options. Opportunities for tele-trials and shared care could be explored.

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

4.5 Support and communication

4.5.1 Supportive care

Refer to the validated screening tools mentioned in Principle 4 ‘Supportive care’.

Specific challenges and needs may arise for patients at this time:

- assistance for dealing with emotional and psychological issues, including body image concerns, fatigue, quitting smoking, traumatic experiences, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns
- potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- management of physical symptoms
- decline in mobility or functional status due to treatment
- assistance with beginning or resuming regular exercise with referral to an exercise physiologist or physiotherapist.[134,211]

Other needs that may arise for rural and remote Australians living with cancer include:

- referral to relevant non-government organisations to provide emotional support, logistical support and information in the diagnostic phase
- support managing extended travel and accommodation needs for treatment, particularly for those requiring specialised care like radiation therapy[177]
- assistance coordinating care between local healthcare providers and urban treatment centres[180]
- help accessing telehealth services (where appropriate) to reduce travel burden for suitable appointments[178]
- financial support for additional costs related to travel, accommodation and time away from work during treatment[181]
- connection to local support networks and patient navigation services to help coordinate ongoing care needs[184]
- support for family caregivers who may need to travel or relocate temporarily to assist with care[185]
- access to culturally appropriate psychosocial support services that consider rural values and circumstances[183]
- assistance managing treatment side effects with limited local cancer specialist support[212]
- help coordinating follow-up care and monitoring between treatments when returning to rural communities[178]
- early identification of formal supports such as allied health and psychosocial supports, including those offered via telehealth where appropriate.

Early involvement of primary healthcare providers may lead to improved cancer care following acute treatment by supporting primary healthcare providers to provide supportive survivorship care close to home. Primary healthcare providers can address many supportive care needs through good communication and clear guidance from the specialist team.[213]

Patients, carers and families may have these additional issues and needs:

- financial issues related to loss of income (through reduced capacity to work or loss of work) and additional expenses due to illness or treatment
- advance care planning, which may involve appointing a substitute decision-maker and completing an advance care directive
- legal issues (completing a will, care of dependent children) or making an insurance, superannuation or social security claim based on terminal illness or permanent disability.

Cancer Council's Cancer Information and Support Service (13 11 20) assists people affected by cancer with practical, financial and emotional support and helps to navigate and access available supportive care services.

For more information on supportive care and needs that may arise for different population groups, refer to Appendices A, B and C.

4.5.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway. If it is required before treatment, it is referred to as prehabilitation (refer to section 3.6.1).

All members of the multidisciplinary team have an important role in promoting rehabilitation. Team members may include occupational therapists, speech pathologists, dietitians, social workers, psychologists, physiotherapists, exercise physiologists and rehabilitation specialists.

To maximise the safety and therapeutic effect of exercise for people with cancer, all team members should recommend that people with cancer work towards achieving, and then maintaining, recommended levels of exercise and physical activity as per relevant guidelines. Exercise should be prescribed and delivered under the direction of an accredited exercise physiologist or physiotherapist with experience in cancer care.[214] The focus of intervention from these health professionals is tailoring evidence-based exercise recommendations to the individual patient's needs and abilities, with a focus on the patient transitioning to ongoing self-managed exercise.

Other issues that may need to be dealt with include managing cancer-related fatigue, improving physical endurance, achieving independence in daily tasks, optimising nutritional intake, returning to work and ongoing adjustment to cancer and its sequels. Referrals to dietitians, psychosocial support, return-to-work programs and community support organisations can help in managing these issues.

Access to allied health professionals may be severely limited in regional, remote and rural areas. Innovative approaches including telehealth and community exercise programs may be integrated into care for people who would otherwise not be able to receive these interventions.

4.5.3 Communication with patients, carers and families

The lead or nominated clinician should take responsibility for these tasks:

- discussing treatment options with patients and carers, including the treatment intent and expected outcomes, and providing a written version of the plan and any referrals
- providing patients and carers with information about the possible side effects of treatment, managing symptoms between active treatments, how to access care, self-management strategies and emergency contacts
- encouraging patients to use question prompt lists and audio recordings, and to have a support person present to aid informed decision-making
- initiating a discussion about advance care planning and involving carers or family if the patient wishes.

4.5.4 Communication with the primary healthcare provider

The primary healthcare provider plays an important role in coordinating care for patients, including helping to manage side effects and other comorbidities, and offering support when patients have questions or worries. For most patients, simultaneous care provided by their primary healthcare provider is very important.

The lead clinician, in discussion with the patient's primary healthcare provider, should consider these points:

- the primary healthcare provider's role in symptom management, supportive care and referral to local services
- using a chronic disease management plan and mental healthcare management plan
- how to ensure regular and timely two-way communication about:
  - the treatment plan, including intent and potential side effects
  - supportive and palliative care requirements
  - the patient's prognosis and their understanding of this
  - enrolment in research or clinical trials
  - changes in treatment or medications
  - the presence of an advance care directive or appointment of a substitute decision-maker
  - recommendations from the multidisciplinary team.

More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 5: Care after initial treatment and recovery

Survivorship care in Australia has traditionally been provided to patients who have completed active treatment and are in the post-treatment phase. But there is now a shift to provide survivorship care and services from the point of diagnosis to improve cancer-related outcomes.

People living with and beyond cancer may experience inferior quality of life and cancer-related symptoms for up to 5 years after their diagnosis.[215] Distress, fear of cancer recurrence, fatigue, obesity and sedentary lifestyle are common symptoms reported by people living with and beyond cancer.[214]

Due to an ageing population and improvements in treatments and supportive care, the number of people surviving cancer is increasing. International research shows there is an important need to focus on helping people living with and beyond cancer cope with life beyond their acute treatment. People living with and beyond cancer often face issues that are different from those experienced during active treatment for cancer and may include a range of issues, as well as unmet needs that affect their quality of life.[216,217]

Physical, emotional and psychological issues include fear of cancer recurrence, cancer-related fatigue, pain, distress, anxiety, depression, cognitive changes and sleep issues.[216] Late effects may occur months or years later and depend on the type of cancer treatment. Survivors and their carers may experience impacted relationships and practical issues including difficulties with return to work or study and financial hardship. They may also experience changes to sex and intimacy. Fertility, contraception and pregnancy care after treatment may require specialist input.

The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes the essential components of survivorship care listed in the paragraph above, including interventions and surveillance mechanisms to manage the issues a person may face.[218] Access to a range of health professions may be required including physiotherapy, occupational therapy, social work, dietetics, clinical psychology, fertility and palliative care. Coordinating care between all providers is essential to ensure the patient's needs are met.

People living with and beyond cancer are more likely than the general population to have and/or develop comorbidities.[219] Health professionals should support survivors to self-manage their own health needs and to make informed decisions about lifestyle behaviours that promote wellness and improve their quality of life.[220,221]

The complexity of healthcare systems means that healthcare services, organisations and providers often work independently to support people living with and beyond cancer which may lead to fragmented care, particularly for those living in rural and remote areas of Australia.[222] Rural people living with and beyond cancer face multifaceted challenges that require comprehensive, personalised approaches to supportive care that address their unique geographical, social and personal circumstances. The literature indicates that rural people living with and beyond cancer experience higher levels of psychological distress and unmet emotional needs,[35] alongside limited access to mental health services and support groups.[223] Cultural norms of self-reliance may further prevent patients from seeking psychological support.[224,225]

Also, rural people encounter substantial gaps in information and support for their recovery,[226] including difficulties in accessing specialised care and follow-up services,[227] with limited availability of local supportive care services[228] and challenges in obtaining comprehensive survivorship care plans.[226] Transportation issues, including significant travel time and financial burdens associated with medical appointments, complicate their survivorship care.[229]

Physical challenges that affect activities of daily living are also prevalent, with higher reports of limitations and treatment-related symptoms[230,231] and difficulties in managing long-term side effects.[56] Limited access to up-to-date cancer information[232] may lead to other communication barriers with healthcare providers,[233] and people living with and beyond cancer in rural and remote areas may be more likely to lack personalised information about diet, lifestyle and self-care.[234]

Financial and practical concerns may contribute to their hardships, as people living with and beyond cancer living in rural and remote areas of Australia have been reported to experience higher financial distress and challenges related to returning to work[235] while simultaneously having limited access to financial support services.[227] Technological barriers, including limited internet access and lower digital literacy, further hinder their access to telemedicine and online support.[229,236,237]

Finally, unique cultural and social factors play a critical role in the support systems of rural and remote living with and beyond cancer. The importance of family and community support has been emphasised[238] and a differing perception of health and wellness, compared with urban people living with cancer and beyond, has been described.[239] Addressing these diverse needs through tailored supportive survivorship care is essential for improving outcomes for rural people.

5.1 Transitioning from active treatment

The transition from active treatment to post-treatment care is critical to long-term health. In some cases, people will need ongoing, hospital-based care, and in other cases a shared follow-up care arrangement with their primary healthcare provider may be appropriate. This will vary depending on the type and stage of cancer and needs to be planned.

Shared follow-up care involves the joint participation of cancer specialists and primary healthcare providers in the planned delivery of follow-up and survivorship care. A shared care plan is developed that outlines the responsibilities of members of the care team, the follow-up schedule, triggers for review, plans for rapid access into each setting and agreement regarding format, frequency and triggers for communication.

After completing initial treatment, a designated member of the multidisciplinary team (most commonly nursing or medical staff involved in the patient's care) should provide the patient with a needs assessment and treatment summary and develop a survivorship care plan in conjunction with the patient. This should include a comprehensive list of issues identified by all members of the multidisciplinary team involved in the patient's care and by the patient. These documents are key resources for the patient and their healthcare providers and can be used to improve communication and care coordination.

The **treatment summary** should cover, but is not limited to:

- The diagnostic tests performed and results
- Diagnosis including stage, prognostic or severity score
- Tumour characteristics
- Treatment received (types and dates)
- Current toxicities (severity, management and expected outcomes)
- Interventions and treatment plans from other health providers
- Potential long-term and late effects of treatment
- Supportive care services provided
- Follow-up schedule
- Contact information for key healthcare providers.

The transition from initial cancer treatment to survivorship care is critical to ensuring long-term health and well-being. For people living with and beyond cancer living in rural and remote areas of Australia, some of these challenges may be more pronounced, and/or they may experience challenges.[240,241]

When transitioning from active cancer care appropriate and timely discussions with the local providers and the patient are crucial in determining if post-acute care will be undertaken by the treating site, the local site, or as a shared care arrangement. It should be noted that local providers may or may not have experience in providing this treatment so support should be provided to local sites if required. Also, the treating site should identify alongside local providers, the supportive care requirements that will be needed to safely discharge the patient back to their local community (e.g. dressings, enteral nutrition, oral targeted therapies) as these may not be routinely stocked or accessible in all areas.

Key considerations for people living with and beyond cancer who live in rural and remote areas of Australia during the transition from active treatment to survivorship care include:

- limited access to follow-up supportive cancer care due to cancer specialist shortages and/or long travel distances[35,226–229]
- lack of trust and choice in local rural healthcare services[241]
- higher rates of cancer-related fatigue, pain and rates between 30 and 70% more likely to experience poorer psychological outcomes than those from urban areas[242,243]
- lower rates of receiving comprehensive survivorship care plans including unclear post-treatment pathways
- lack of information on prognosis and recovery, referrals to support services and lifestyle advice[226]
- the need to provide and re-iterate information at multiple timepoints, using an accessible mode and timing of delivery, aligned and sensitive to the current health and emotional state
- in some communities, the lack of longitudinal continuity of the providers of primary care can reduce adherence to local policies and processes. Shared surveillance with general practice needs to consider geographically specific factors.[83]

5.2 Follow-up care

Responsibility for follow-up care should be agreed between the lead clinician, the primary healthcare provider, relevant members of the multidisciplinary team and the patient. This is based on guideline recommendations for post-treatment care, as well as the patient's current and anticipated physical and emotional needs and preferences.

Due to the high reliance on the primary healthcare provider in rural and remote health settings, it is important that the primary healthcare provider is included in MDT discussions regarding treatment planning and follow-up care to effectively support this once a person returns home.

Evidence comparing shared follow-up care and specialised care indicates equivalence in outcomes including recurrence rate, cancer survival and quality of life.[6]

Ongoing communication between healthcare providers involved in care and a clear understanding of roles and responsibilities is key to effective survivorship care.

In particular circumstances, other models of post-treatment care can be safely and effectively provided such as nurse-led models of care.[244] Other models of post-treatment care can be provided in these locations or by these health professionals:

- in a shared care setting
- in a general practice setting
- by non-medical staff
- by allied health or nurses
- in a non-face-to-face setting (e.g. by telehealth).

A designated member of the team should document the agreed survivorship care plan. The survivorship care plan should support wellness and have a strong emphasis on healthy lifestyle changes such as a balanced diet, a non-sedentary lifestyle, weight management and a mix of aerobic and resistance exercise.[134,211]

This survivorship care plan should also cover, but is not limited to:

- what medical follow-up is required (surveillance for recurrence or secondary and metachronous cancers, screening and assessment for medical and psychosocial effects)
- model of post-treatment care, the health professional providing care and where it will be delivered
- care plans from other health providers to manage the consequences of cancer and cancer treatment
- wellbeing, primary and secondary prevention health recommendations that align with chronic disease management principles
- rehabilitation recommendations
- available support services
- a process for rapid re-entry to specialist medical services for suspected recurrence.

Survivors generally need regular follow-up, often for 5 or more years after cancer treatment finishes. If treatment has taken place at a larger regional or metropolitan centre, but the patient lives in a rural and remote area, the follow-up must also include communication back to the local care team. The survivorship care plan therefore may need to be updated to reflect changes in the patient's clinical and psychosocial status and needs.

Processes for rapid re-entry to hospital care should be documented and communicated to the patient and relevant stakeholders.

Care in the post-treatment phase is driven by predicted risks (e.g. the risk of recurrence, developing late effects of treatment and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is based on evidence and is consistent with guidelines. Not all people will require ongoing tests or clinical review and may be discharged to general practice follow-up.

The lead clinician should discuss (and primary healthcare provider reinforce) options for follow-up at the start and end of treatment. It is critical for optimal aftercare that the designated member of the treatment team educates the patient about the symptoms of recurrence.

GPs and specialist nurses can:

- connect patients to local community services and programs including survivorship programs that connect patients with peer support networks in their communities
- manage long-term and late effects
- manage comorbidities
- provide wellbeing information and advice to promote self-management
- screen for cancer and non-cancerous conditions
- use telehealth for follow-up consultations with patients.

More information

Templates and other resources to help with developing treatment summaries and survivorship care plans are available from these organisations:

- Australian Cancer Survivorship Centre
- Cancer Australia – Principles of Cancer Survivorship
- Cancer Council Australia and states and territories
- Clinical Oncology Society of Australia – Model of Survivorship Care
- eviQ – Cancer survivorship: introductory course
- mycareplan.org.au
- South Australian Cancer Service – Statewide Survivorship Framework resources
- American Society of Clinical Oncology – guidelines.

5.2.1 Preventing recurrence

Not smoking, eating a healthy diet, being sun smart, avoiding or limiting alcohol intake, being physically active and maintaining a healthy body weight may help reduce the risk of primary recurrence or a second primary cancer.

Care for all people living with and beyond cancer should include proactive support and coordination between providers, ensuring that any comorbidities—particularly ongoing, complex, or life-threatening conditions—are appropriately managed.

5.3 Research and clinical trials

Support people living with and beyond cancer to participate in research or clinical trials where they are available and appropriate. These might include studies to understand survivors' issues, to better manage treatment side effects, or to improve models of care and quality of life. Also explore opportunities for tele-trials and shared care.

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

5.4 Support and communication

5.4.1 Supportive care

Refer to the validated screening tools mentioned in Principle 4 'Supportive care'. Also, the 'Cancer Survivors Unmet Needs (CaSun)' is another validated screening tool that may help health professionals to identify the unmet needs of patients during survivorship.

A number of specific challenges and needs may arise for people living with and beyond cancer:

- financial and employment issues (such as loss of income and assistance with returning to work, and the cost of treatment, travel and accommodation)
- appointing a substitute decision-maker and completing an advance care directive
- legal issues such as completing a will.

Other needs that may arise for rural and remote Australians living with cancer include:

- physical and daily living:
  - support for managing long-term treatment effects and compromised immunity[245,246]
  - access to physical rehabilitation, occupational therapy, lymphoedema and exercise programs[247]
- healthcare access:
  - transportation assistance for follow-up appointments[248]
  - improved access to specialised survivorship care resources[249]
  - better coordination with healthcare teams[56]
- financial and employment support:
  - financial navigation services tailored to rural circumstances[246] circumstances[250]
  - support for return-to-work transitions, particularly given limited rural job markets and that some people are self-employed[245]
  - assistance with disability benefits applications[251]
- psychosocial support:
  - access to mental health services and support groups[56]
  - information about self-management strategies[249]
  - support for managing changes in family and social relationships.[246,248]

For more information on supportive care and needs that may arise for different population groups, refer to Appendices A, B and C.

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway from the pre-treatment phase through to disease-free survival and palliative care.[167]

Issues that may need to be dealt with include managing cancer-related fatigue, coping with cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to study or work and ongoing adjustment to cancer and its sequels.

Exercise is a safe and effective intervention that improves the physical and emotional health and wellbeing of cancer patients. Exercise should be embedded as part of standard practice in cancer care and be viewed as an adjunct therapy that helps counteract the adverse effects of cancer and its treatment.

People living with and beyond cancer may find referral to specific cancer rehabilitation, optimisation programs or community-based rehabilitation appropriate and beneficial. Other options include referral to allied health supports through team care arrangements and mental health plans. Some community support organisations (cancer-related non-government, not-for-profit and charities) provide services to people living with and beyond cancer.

5.4.3 Communication with patients, carers and families

The lead clinician (themselves or by delegation) should take responsibility for these tasks:

- explaining the model of post-treatment care and the roles of health professionals involved in post-treatment care including the role of general practice
- explaining the treatment summary and follow-up care plan
- discussing the development of a shared follow-up and survivorship care plan where a model of shared follow-up care has been agreed
- discussing how to manage any of the physical, psychological or emotional issues identified
- providing information on the signs and symptoms of recurrent disease
- providing a survivorship care plan with information on secondary prevention and healthy living
- providing contact details of the care team involved
- providing clear information about the role and benefits of palliative care and advance care planning.

5.4.4 Communication with the primary healthcare provider

The lead clinician should ensure regular, timely, two-way communication with the primary healthcare provider about:

- the patient's progress
- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- any shared care arrangements
- clarification of various roles in patient care
- a process for rapid re-entry to medical services for patients with suspected recurrence or if there are other concerns.

More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 6: Managing recurrent, residual or metastatic disease

Patients who present with recurrent, residual, metastatic or advanced disease should be managed by a multidisciplinary team and offered timely referral to appropriate physical, practical and emotional support.

Step 6 is concerned with managing recurrent or local residual and metastatic disease. The likelihood of recurrence depends on many factors usually related to the type of cancer, the stage of cancer at presentation and the effectiveness of treatment. Some cancers cannot be eradicated even with the best initial treatment. But controlling disease and disease-related symptoms is often possible, depending on the clinical situation.

6.1 Signs and symptoms of metastatic disease

Some patients will have metastatic disease on initial presentation. Others may present with symptoms of recurrent disease after a previous cancer diagnosis. Access to the best available therapies, including clinical trials, as well as treatment overseen by a multidisciplinary team, are crucial to achieving the best outcomes for anyone with metastatic disease.

Signs and symptoms will depend on the type of cancer initially diagnosed and the location of metastatic disease. They may be discovered by the patient or by surveillance in the post-treatment period.

6.2 Managing metastatic disease

Managing metastatic disease is complex and should therefore involve all the appropriate specialties in a multidisciplinary team including palliative care where appropriate. From the time of diagnosis, the team should offer patients appropriate psychosocial care, supportive care, advance care planning and symptom-related interventions as part of their routine care. The approach should be personalised to meet the patient's individual needs, values and preferences. The full complement of supportive care measures as described throughout the optimal care pathway and in Appendices A, B and C should be offered to assist patients and their families and carers to cope. These measures should be updated as the patient's circumstances change.

Survivorship care should be considered and offered at an early stage. Many people live with advanced cancer for many months or years. As survival is improving in many patients, survivorship issues should be considered as part of routine care. Health professionals should therefore be ready to change and adapt treatment strategies according to disease status, prior treatment tolerance and toxicities and the patient's quality of life, as well as the patient's priorities and life plans.

6.3 Multidisciplinary team

If a patient's cancer has returned, provide care under the guidance of a treating cancer specialist. This care should be coordinated by the patient's primary healthcare provider. Referral back to the original team and other multidisciplinary teams is optimal, specifically to discuss novel aspects of care, which may involve different therapeutic and supportive care disciplines than when initially discussed. Appropriate care should not depend on returning to a multidisciplinary team; additional care, such as palliative medicine and consideration of clinical trials, can be undertaken by the local clinician who is a member of the multidisciplinary team.

6.4 Treatment

Treatment will depend on the location, extent of recurrent or residual disease, previous management and the patient's preferences.

Details for appropriate treatments and optimal timeframes are outlined in each cancer-specific optimal care pathway.

The potential goals of treatment should be discussed, respecting the patient's cultural values. Wherever possible, written information should be provided.

Encourage early referral to clinical trials or accepting an invitation to participate in research.

6.5 Advance care planning

Advance care planning is important for all patients with a cancer diagnosis but especially those with advanced disease. Patients should be encouraged to think and talk about their healthcare values and preferences with family or carers, appoint a substitute decision-maker and consider developing an advance care directive to convey their preferences for future healthcare in the event they become unable to communicate their wishes.

Patients and their families and supporters should be provided with written information to take home about advance care planning.

More information

Refer to section 4.3 'More information' for links to resources.

Refer patients and carers to Advance Care Planning Australia <www.advancecareplanning.org.au> or to the Advance Care Planning National Phone Advisory Service on 1300 208 582.

6.6 Palliative care

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits.[206-208] The treatment team should emphasise the value of palliative care in improving symptom management and quality of life to patients and their carers. Refer to section 4.3 for more detailed information.

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on the patient's need and potential for benefit, not prognosis.

Where access to a palliative care physician or team is limited, tele-nursing should be explored to connect patients to a suitable palliative care alternative. Telehealth-facilitated models of palliative care are a patient-focused way to facilitate specialist care in or closer to home for people with a life-limiting illness.[252,253]

People living with cancer in rural areas often prefer to die at, or close to, home, but multiple barriers (including limited access to healthcare services, geographical constraints and socioeconomic factors) reduce the likelihood of this preference being realised.[254] To support rural patients to return home, it is important to expand home-based or facility-based homelike hospice respite or end-of-life care, improve healthcare access and address sociodemographic disparities. These are critical steps in ensuring people living with cancer in rural areas receive end-of-life care in their preferred setting. While specialist palliative care services aim to be accessible, their availability can differ between rural and urban areas, though rural patients may rely more on social networks rather than close family for hands-on care.

Community-based palliative care models in rural areas are diverse, leveraging primary healthcare providers, telehealth, community health workers and volunteers to improve access. Sustainable models require collaboration between local healthcare teams, policymakers and rural communities to address unique geographical and resource challenges.[64,255–259]

Rural palliative care service use is characterised by significant disparities, limited access and unique challenges that require comprehensive, multifaceted solutions. Barriers such as longer distances to care facilities[260] and limited healthcare infrastructure hinders access to specialised palliative care services.

Also, demographic factors, such as lower socioeconomic status and racial and ethnic minority status, correlate with reduced access to palliative care.[261] Older patients are less likely to receive comprehensive palliative care and often rely more on primary healthcare providers for end-of-life care.[262]

Emerging technology-based solutions, such as telemedicine and virtual hospice models, offer promising approaches to overcoming geographical barriers.[263,264] But challenges remain, including fragmented service delivery and difficulties in transitioning between care settings.[265] When a new diagnosis of a recurrent or metastatic disease the patient should be discussed at the MDM to ensure access to clinical trials and that best practice care is provided. By addressing these gaps through innovative care models and technology, palliative care access and quality for rural populations can be improved.

More information

Refer to the end of section 4.3 'Palliative care' for links to resources.

6.7 Research and clinical trials

The treating team should be aware of potential clinical trials, particularly for emerging treatments and rare, hard-to-treat cancers, for which there may be limited evidence on how the condition is best treated or managed.[210] This may mean identifying clinical trials outside the treating centre. These clinical trial opportunities should be discussed with potential participants so they can consider their options. Also explore opportunities for tele-trials and shared care.

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

6.8 Support and communication

6.8.1 Supportive care

Refer to the validated screening tools mentioned in Principle 4 'Supportive care'.

A number of specific challenges and needs may arise at this time for patients:

- assistance for dealing with emotional and psychological distress resulting from fear of death or dying, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns (also support the patients' family and carers)
- potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- cognitive changes due to treatment and disease progression such as altered memory, attention and concentration (a patient may appoint someone to make medical, financial and legal decisions on their behalf – a substitute decision-maker – before and in case they experience cognitive decline)
- management of physical symptoms
- decline in mobility or functional status due to recurrent disease and treatments (referral to physiotherapy or occupational therapy may be required)
- coping with hair loss and changes in physical appearance (refer to the Look Good, Feel Better program – see 'Resource list')
- appointing a substitute decision-maker and completing an advance care directive
- financial issues due to disease recurrence such as gaining early access to superannuation and insurance
- legal issues (completing a will, care of dependent children) and making an insurance, superannuation or social security claim based on terminal illness or permanent disability.

Other challenges and needs that may arise at this time for patient for rural and remote Australians living with cancer include:

- limited access to specialised palliative care services, particularly in rural areas[266]
- transportation barriers for accessing treatment and follow-up care, often requiring long-distance travel[267]
- need for coordinated care between local healthcare providers and urban treatment centres[268]
- rapid turnover of primary healthcare providers in rural and remote areas, resulting in a lack of continuity of care
- financial burden from travel costs and accommodation when accessing distant specialist services[269]
- challenges accessing timely symptom management support, particularly for breakthrough pain and other acute symptoms[270]
- limited access to psychosocial support services and support groups in rural communities[271]
- need for enhanced communication between rural primary healthcare providers and urban cancer specialist teams[272]
- greater reliance on family caregivers who may experience higher burden due to limited formal support services.[273]

6.8.2 Rehabilitation

Rehabilitation may be required at any point of the metastatic care pathway, from preparing for treatment through to palliative care. Issues that may need to be dealt with include managing cancer-related fatigue, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to cancer and its sequels.

Exercise is a safe and effective intervention that improves the physical and emotional health and wellbeing of cancer patients. Exercise should be embedded as part of standard practice in cancer care and be viewed as an adjunct therapy that helps counteract the adverse effects of cancer and its treatment.

6.8.3 Communication with patients, carers and families

The lead clinician should ensure there is adequate discussion with patients and carers about the diagnosis and recommended treatment, including treatment intent and possible outcomes, likely adverse effects and the supportive care options available.

More information

Refer to Principle 6 ‘Communication’ for communication skills training programs and resources.

Step 7: End-of-life care

Step 7 is concerned with maintaining the patient's quality of life and meeting their health and supportive care needs as they approach the end of life, as well as the needs of their family and carers.

Some patients with advanced cancer will reach a time when active treatment is no longer appropriate. The team needs to share the principles of a palliative approach to care when making decisions with the patient and their family or carer. Palliative care looks to manage a patient's symptoms and quality of life when disease may not be curable. End-of-life care is appropriate when the patient's symptoms are increasing and functional status is declining.

Every Australian should have equitable access to palliative care. Referral to palliative care should be made when curative intent as a treatment is no longer an option but before treatment ceases. End-of-life care for cancer patients in rural and remote Australia presents significant challenges in access and service delivery. Research shows that rural patients face substantial geographical barriers to accessing palliative care services, with notably lower rates of inpatient palliative care use and higher rates of emergency department visits compared with metropolitan areas.[274] Considering these access barriers, palliative support should be offered more broadly through symptom management in the absence of a defined palliative service.

Healthcare use patterns in the last year of life reveal distinct differences between rural and urban settings. Rural patients show higher emergency department usage and greater reliance on acute hospital services, primarily due to limited community-based options (i.e. community nursing).[275] This disparity is further complicated by resource constraints and limited availability of specialist palliative care providers in rural areas.[276]

Several key barriers affect the delivery of quality end-of-life care in rural settings. These include the significant distances patients must travel to access service centres, difficulties in coordinating care between multiple healthcare providers and persistent resource constraints affecting service delivery.[277] However, emerging solutions show promise in addressing these challenges. These include integrated care models that link rural and metropolitan services, increased use of telehealth for cancer specialist consultations and strengthened partnerships between local healthcare providers and specialist palliative care services.[259,278,279] A proactive approach to discussing palliative care options with patients can often create a better experience where patients are informed early and can establish better relationships with the palliative support team. Talking about end-of-life and palliative care with Aboriginal and Torres Strait Islander people can be difficult. It's important to use culturally sensitive approaches and consider alternative language when discussing palliative care – for example, 'comfort care'.

A person who is suffering in the late stages of advanced disease and who meets strict criteria can request access to voluntary assisted dying (VAD). It must be voluntary and initiated by the person themselves.

As VAD is legislated by state and territory governments, it is essential to know the law and rules around this choice in the state or territory where the patient lives.[280] Contact your state's health department for the latest voluntary assisted dying information relevant to your state.

In jurisdictions where VAD is legal, there is evidence that people from rural and remote areas of Australia experience greater barriers to access than their counterparts in metropolitan areas.[281,282] For example, there have been several initiatives implemented to improve access for rural and remote Australians, including broadened qualifications for medical practitioners who can take part in VAD and establishing the Statewide Care Navigator Service.[283]

Find more information about VAD online <www.gogentleaustralia.org.au>.

While progress has been made in providing end-of-life care to rural cancer patients, significant disparities remain in access and service availability compared with metropolitan areas. The evidence suggests that continued focus on innovative service delivery models and enhanced coordination of care is needed to improve outcomes for rural cancer patients approaching the end of life.

More information

Contact your state's health department for the latest voluntary assisted dying information relevant to your state <www.health.gov.au/about-us/contact-us/local-state-and-territory-health-departments>.

7.1 Multidisciplinary palliative care

If the treatment team does not include a palliative care member, the lead clinician should consider referring the patient to palliative care services, with the primary healthcare provider's engagement. This may include inpatient palliative unit access (as required).

In urban areas end-of-life care is often delivered by a multidisciplinary team. However, in rural and remote areas, primary healthcare providers are often engaged to support end-of-life care.[284] With extra barriers to accessing palliative care and end-of-life services in rural and remote areas, the responsibility for initiating the discussion should be shared among the treating team. End-of-life and palliative care services may be better known to the clinician providing services closest to the patient's home, highlighting the need for effective communication between treating clinicians.

The multidisciplinary team may consider seeking expertise from these professionals:

- clinical psychologist
- clinical nurse specialist or practitioner
- social worker
- palliative medicine specialist
- pain specialist
- pastoral or spiritual carer
- bereavement counsellor
- music therapist
- art therapist
- cultural expert.

The team might also recommend that patients access these services:

- home and community-based care
- specialist community palliative care workers
- community nursing.

Funding for practitioners to conduct home visits can be a barrier to delivering care to rural and remote Australians.[284]

If the patient does not already have an advance care directive in place, a designated member of the treatment team should encourage them to develop one in collaboration with their family or carer.

It is essential for the treatment team to consider the appropriate place of care, the patient's preferred place of death and the support needed for the patient, their family and carers in consultation with the patient and their family.

The treatment team should also ensure that carers and families receive written information, support and guidance about their role according to their needs and wishes.[209]

More information

The treatment team can refer patients and carers to these resources:

- Palliative Care Australia <www.palliativecare.org.au>
- Advance Care Planning Australia <www.advancecareplanning.org.au> or to Advance Care Planning Australia's National Advisory Service on 1300 208 582.

7.2 Research and clinical trials

Research and clinical trials are also essential for end-of-life cancer care as they provide the evidence base needed to determine which interventions improve quality of life and care for patients. Palliative care physicians are best placed to lead this research and discuss opportunities with patients and their families.

Patients may be able to participate in research outside of their treating organisations, particularly survey-type research that provides valuable insights into the lived experience of people with cancer. Such research may be completed over the phone or via an electronic survey link. Also explore opportunities for tele-trials and shared care.

Statewide palliative care tele-trial cluster – Queensland

In 2024 Queensland launched a statewide palliative care tele-trial cluster randomised controlled trial.[285] The clinical trial investigates medicinal cannabis for advanced cancer symptoms. Mater Health and the Queensland Regional Clinical Trial Coordinating Centre co-designed the palliative care trial, linking Queensland's 15 hospital and health services as satellite sites to Mater Health. This innovative model differs from other tele-trial models because it uses existing health jurisdictions to create a statewide research cluster. This is significant because this approach has the potential to expand clinical trial access throughout Australia. The first site was activated in 2024 at the Central West health service, a remote region of Queensland servicing about 10,000 people. As of December 2025, a total of 9 sites have been activated. Because those living in rural and remote areas may have reduced access to palliative care and clinical trials, the statewide palliative care tele-trial cluster represents an important initiative for improving equitable cancer care.

For more information visit the Cancer Australia website <www.australiancancertrials.gov.au>. Refer to the 'Resource list' for more clinical trial databases.

7.3 Support and communication

7.3.1 Supportive care

Refer to the validated screening tools mentioned in Principle 4 'Supportive care'.

Specific challenges and needs may arise for patients at this time:

- assistance for dealing with emotional and psychological distress from anticipatory grief, fear of death or dying, anxiety/depression and interpersonal problems
- management of physical symptoms
- decline in mobility or functional status, affecting the patient's discharge destination (a referral to physiotherapy, exercise physiology, occupational therapy or social work may be needed)
- appointing a substitute decision-maker and completing an advance care directive
- legal issues (completing a will, care of dependent children) and making an insurance, superannuation or social security claim based on terminal illness or permanent disability
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs
- arranging a funeral.

Other needs that may arise for rural and remote Australians living with cancer include:

- access to after-hours palliative care support and emergency services, particularly in areas without 24/7 coverage[286]
- access to after-hours pain medication pathways (including someone to deliver them), which need to be embedded and functioning to ensure no delays to prescribing end-of-life medication – it can take many days for some drugs (such as opioids) to be delivered; therefore, anticipatory prescribing and planning for deterioration is important
- coordination between local primary healthcare providers and urban cancer specialist services through telehealth where available[272]
- support for family caregivers including education in pain management and end-of-life care, given limited access to professional services[287]
- support for facilitating death at home if desired, including access to necessary equipment and medications[268]
- cultural considerations specific to rural communities in end-of-life care preferences and delivery.[288]

These services and resources can help:

- The National Core Community Palliative Care Medicines List which provides information regarding medicines for use with home-based palliative patients <https://palliativecare.org.au/product/national-core-community-palliative-care-medicines-list>
- referral to 13 11 20 for Cancer Council's Pro Bono Program for free legal, financial, small business accounting and workplace assistance (subject to a means test)
- *Sad news sorry business*[289] for the specific needs of Aboriginal and Torres Strait Islander people.

For more information on supportive care and needs that may arise for different population groups, refer to Appendices A, B and C.

7.3.2 Communication with patients, carers and families

The treatment team is responsible for:

- being open to and encouraging discussion with the patient about the expected disease course, considering the patient's personal and cultural beliefs and expectations
- discussing palliative care options, including inpatient and community-based services as well as dying at home and subsequent arrangements – this discussion should begin at the time of diagnosis of incurable disease, and at the latest when active treatment is stopped
- promoting patient education and agency in decision-making
- providing the patient and carer with the contact details of a palliative care service
- referring the patient to palliative care in the community according to the carer's wishes.

7.3.3 Communication with the primary healthcare provider

The lead clinician should discuss end-of-life care planning to ensure the patient's needs and goals are met in the appropriate environment. The patient's primary healthcare provider must be kept fully informed and involved in major developments in the patient's illness path, including changes in medication regimen or the end of active treatment. It is important to ensure communication about the death of a patient is shared with the treating team.

More information

For support with communication skills and training programs, refer to these sources:

- *Sad news sorry business* <www.health.qld.gov.au/__data/assets/pdf_file/0023/151736/sorry_business.pdf>
- Principle 6 'Communication'.

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Australia New Zealand Gynaecological Oncology Group (ANZGOG)

Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG)

Australian and New Zealand Head and Neck Cancer Society (ANZHNCS)

Australian and New Zealand Society of Palliative Medicine (ANZSPM)

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Australian Society of Medical Imaging and Radiation Therapy (ASMIRT)

BEAT Bladder Cancer Australia

Bowel Cancer Australia

Brain Tumour Alliance Australia (BTAA)

Brisbane North Primary Health Network

Brisbane South Primary Health Network

Can Assist Inc.

Can Too Foundation

Cancer Council ACT

Cancer Council Australia

Cancer Council New South Wales

Cancer Council Northern Territory

Cancer Council Queensland

Cancer Council South Australia

Cancer Council Tasmania

Cancer Council Victoria

Cancer Council Western Australia

Cancer Nurses Society of Australia (CNSA)

Cancer Voices Australia

Canteen (Australia)

Capital Health Network (ACT Primary Health Network)

Central and Eastern Sydney Primary Health Network

Central Queensland, Wide Bay, Sunshine Coast Primary Health Network

Children's Cancer Institute

Clinical Oncology Society of Australia (COSA)

Commission on Excellence and Innovation in Health (CEIH)

Community Broadcasting Association of Australia (CBAA)

Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINAM)

Consumers Health Forum of Australia (CHF)

Country South Australia Primary Health Network

Country WA Primary Health Network

Darling Downs and West Moreton Primary Health Network

Eastern Melbourne Primary Health Network

Gather My Crew

Gippsland Primary Health Network

Gold Coast Primary Health Network

Head and Neck Cancer Australia

Health Translation South Australia

Hunter New England and Central Coast Primary Health Networ

Inherited Cancers Australia

Leukaemia Foundation

Little Big Steps

Liver Foundation

Lung Foundation Australia

Lymphoma Australia

Medical Oncology Group of Australia (MOGA)

Melanoma Patients Australia

Movember Foundation

Murray Primary Health Network

Myeloma Australia

National Aboriginal Community Controlled Health Organisation (NACCHO)

National Breast Cancer Foundation (NBCF)

National Rural Health Alliance (NRHA)

Nepean Blue Mountains Primary Health Network

NeuroEndocrine Cancer Australia

North Coast Primary Health Network

North Western Melbourne Primary Health Network

Northern Queensland Primary Health Network

Northern Sydney Primary Health Network

Northern Territory Primary Health Network

Omico

Ovarian Cancer Australia

Palliative Care Australia

Pancare Foundation

Pancreatic Cancer Alliance

Perth North Primary Health Network

Perth South Primary Health Network

Primary Health Tasmania (Tasmania Primary Health Network)

Prostate Cancer Foundation of Australia (PCFA)

Queensland Aboriginal and Islander Health Council (QAIHC)

Rare Cancers Australia

Redkite

Royal Australasian College of Dental Surgeons (RACDS)

Royal Australasian College of Physicians

Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Royal Australian and New Zealand College of Radiologists

Royal Australian College of General Practitioners

Royal Australian College of Surgeons

Royal College of Pathologists of Australasia

Royal Flying Doctor Service of Australia

Rural Doctors Association of Australia (RDAA)

So Brave

South Eastern Melbourne Primary Health Network

South Eastern New South Wales Primary Health Network

South Western Sydney Primary Health Network

Sydney North Health Network

Tasman Radiation Oncology Group (TROG Cancer Research)

The Equitable Cancer Outcomes across Rural and Remote Australia National Consumer Program

The Haematology Society of Australia and New Zealand (HSANZ)

The Lift Cancer Care Foundation

Victorian Comprehensive Cancer Centre Alliance

Western New South Wales Primary Health Network

Western Queensland Primary Health Network

Western Sydney Primary Health Network

Western Victoria Primary Health Network

Note: People who registered interest to be notified of the public consultation who represent other organisations are not included on this list.

Appendix A: Supportive care domains

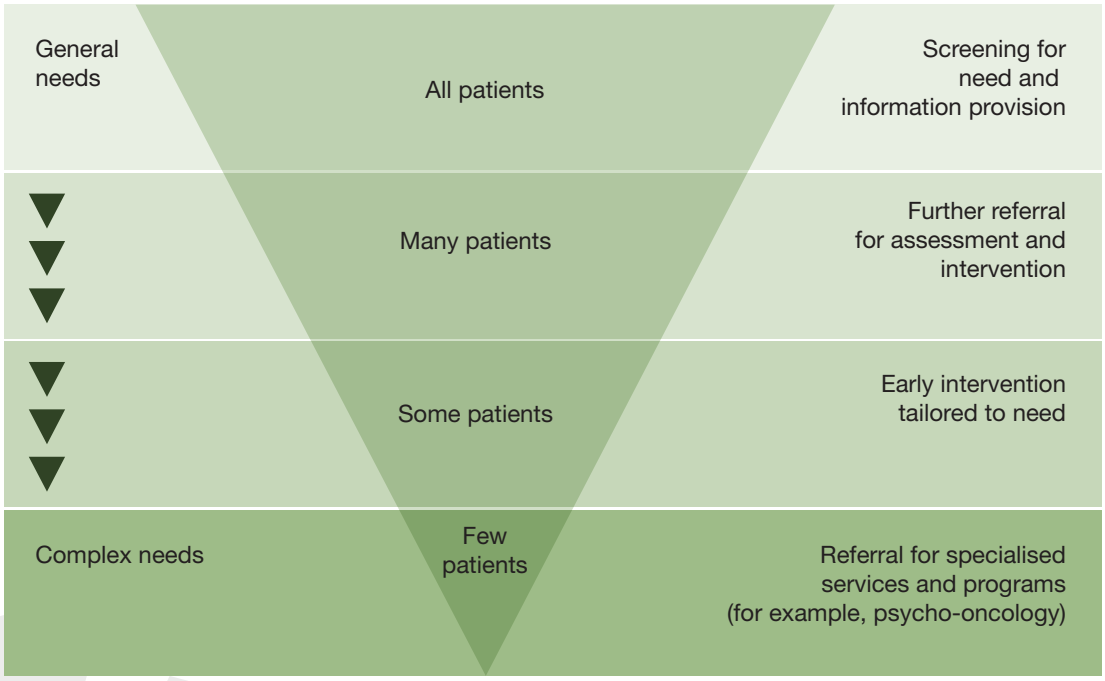
Supportive care in cancer refers to the following 5 domains:

- the physical domain, which includes a wide range of physical symptoms that may be acute, relatively short lived or ongoing, requiring continuing interventions or rehabilitation
- the psychological domain, which includes a range of issues related to the patient's mental health wellbeing and personal relationships
- the social domain, which includes a range of social and practical issues that will affect the patient, carer and family such as the need for emotional support, maintaining social networks and financial concerns
- the information domain, which includes access to information about cancer and its treatment, recovery and survivorship support services and the health system overall
- the spiritual domain, which focuses on the patient's changing sense of self and challenges to their underlying beliefs and existential concerns.[290]

Fitch's model of supportive care recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual patient (Figure A1).[291]

The model targets the type and level of intervention required to meet patients' supportive care needs.

Figure A1: Fitch's tiered approach to supportive care



Appendix B: Psychological needs

Consider a referral to a psychologist, psychiatrist, pastoral/spiritual care practitioner, social worker, specialist nurse or a relevant community-based program if the patient has these issues:

- displaying emotional cues such as tearfulness, distress that requires specialist intervention, avoidance or withdrawal
- being preoccupied with or dwelling on thoughts about cancer and death
- displaying fears about the treatment process or the changed goals of their treatment
- displaying excessive fears about cancer progression or recurrence
- worrying about loss associated with their daily function, dependence on others and loss of dignity
- becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
- feeling hopeless and helpless about the effect that cancer is having on their life and the disruption to their life plans
- struggling to communicate with family and loved ones about the implications of their cancer diagnosis and treatment
- experiencing changes in sexual intimacy, libido and function
- struggling with the diagnosis of metastatic or advanced disease
- having difficulties quitting smoking (refer to Quitline on 13 7848) or with other drug and alcohol use
- having difficulties transitioning to palliative care.

Other considerations that may arise for the multidisciplinary team include:

- support for the carer – encourage referrals to psychosocial support from a social worker, psychologist or GP
- referral to an exercise physiologist or physiotherapist as a therapeutic approach to prevent and manage psychological health
- referral to wellness-after-cancer programs to provide support, information and offer strategies.

Appendix C: Special population groups

The burden of cancer is not evenly spread across Australia. People experiencing socioeconomic disadvantage, Aboriginal and Torres Strait Islander communities, culturally diverse communities, people living with a disability, people with chronic mental health or psychiatric concerns and those who live in regional and rural areas of Australia have poorer cancer outcomes.

Aboriginal and Torres Strait Islander people

Cancer is the third leading cause of burden of disease for Aboriginal and Torres Strait Islander people. While Australia's cancer survival rates are among the best in the world, Aboriginal and Torres Strait Islander people continue to experience a different pattern of cancer incidence and significant disparities in cancer outcomes compared with non-Indigenous Australians.

For Aboriginal and Torres Strait Islander people, health and connection to land, culture, community and identity are intrinsically linked. Health encompasses a whole-of-life view and includes a cyclical concept of life–death–life.

The distinct epidemiology of cancer among Aboriginal and Torres Strait Islander people, and unique connection to culture, highlight the need for a specific optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. Ensuring this pathway is culturally safe and supportive is vital to tackling the disparities for Aboriginal and Torres Strait Islander people.

Published in 2024, the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer, 2nd edition,* provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer across the cancer continuum.

In addition to the key principles underpinning cancer-specific pathways, these are the key concepts that are fundamental to Aboriginal and Torres Strait Islander health:

- providing a holistic approach to health and wellbeing
- providing a culturally appropriate and culturally safe service
- acknowledging the diversity of Aboriginal and Torres Strait Islander people
- understanding the social determinants and cultural determinants of health.[292]

To view the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer, 2nd edition*, visit the Cancer Australia website <https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/OCP-aboriginal-and-torres-strait-islander-people-cancer-second-edition>.

To view the consumer resources – *Checking for cancer* and *Cancer*, visit the Cancer Australia website <https://www.cancer.org.au/cancercareguides/for-aboriginal-and-torres-strait-islanders/checking-for-cancer>.

People from culturally and linguistically diverse backgrounds

For people from culturally diverse backgrounds in Australia, a cancer diagnosis can come with added complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in people from culturally diverse backgrounds, and this can affect their understanding and decision-making after a cancer diagnosis. In addition to different cultural beliefs, when English language is limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for patients.

A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those with a non-Anglo culture, and members of the treatment teams should pay particular attention to supporting these patients.

The Australian Cancer Survivorship Centre has developed a glossary of more than 700 cancer terms in 9 different languages. The multilingual glossary has been designed as a resource for professional translators, interpreters and bilingual health professionals working in the cancer field. The glossary is a unique tool that enables language professionals with access to accurate, consistent and culturally appropriate terminology.

Visit the Peter Mac website <www.petermac.org/multilingualglossary> to see the glossary.

People living with disability

Disability, which can be physical, intellectual or psychological, may have existed before the cancer diagnosis or may be new in onset (occurring due to the cancer treatment or incidentally). Adjusting to life with a disability adds another challenge to cancer care and survivorship.

Several barriers prevent people with disabilities from accessing timely and effective healthcare:[293]

- physical limitations
- competing health needs
- the trauma of undergoing invasive procedures
- potential barriers associated with obtaining informed consent
- failure to provide assistance with communication
- lack of information
- discriminatory attitudes among healthcare staff.

In caring for people with disabilities and a cancer diagnosis, the Australian Institute of Health and Welfare disability flag should be used at the point of admittance to correctly identify and meet the additional requirements of a person with disability. Facilities should actively consider access requirements, and health practitioners should make reasonable adjustments where required.

Patients aged between 7 and 65 years who have a permanent or significant disability may be eligible for support or funding through the National Disability Insurance Scheme.[294]

More information can be found on the NDIS website <www.ndis.gov.au>.

Patients aged 65 years or older (50 years or older for Aboriginal or Torres Strait Islander people) may be eligible for subsidised support and services through aged care services. An application to determine eligibility can be completed online over the phone. More information can be found at the My Aged Care website <www.myagedcare.gov.au>.

More information

'Talking End of Life' is a resource that shows how to teach people with intellectual disability about end of life. It is designed for disability support workers but is also helpful for others including families, health professionals and educators.

To view the resource, visit the Talking End of Life website <www.caresearch.com.au/tel/>.

Older adults

Planning and delivering appropriate cancer care for older people can present a number of challenges. This could also be true for frail people or those experiencing comorbidities. Effective communication between oncology and geriatrics departments will help facilitate best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as the implications of cognitive impairment on suitability of treatment and consent.[295]

At a national interdisciplinary workshop convened by the Clinical Oncology Society of Australia, it was recommended that people over the age of 70 undergo some form of geriatric assessment, in line with international guidelines.[296,297] Screening tools can be used to identify those patients in need of a comprehensive geriatric assessment.[298] This assessment can be used to help determine life expectancy and treatment tolerance and guide appropriate referral for multidisciplinary intervention that may improve outcomes.[299]

Frailty is not captured through traditional measures of performance status (e.g. the Eastern Cooperative Oncology Group) and includes assessment in the domains of:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Published in 2025, the *Optimal care pathway for older people with cancer* guides health practitioners and service planners on optimal care for older people with cancer across the cancer continuum.

View the *Optimal care pathway for older people with cancer* on the Cancer Council website <https://www.cancer.org.au/assets/pdf/optimal-care-pathway-for-older-people-with-cancer>. To view the consumer resources – *For older people with cancer – Your guide to best cancer care* visit the Cancer Council website <https://www.cancer.org.au/cancercareguides/older-people-with-cancer>.

Adolescents and young adults

In recent years, adolescent and young adult oncology has emerged as a distinct field due to lack of progress in survival and quality-of-life outcomes.[300–302] The significant developmental change that occurs during this life stage complicates a diagnosis of cancer, often leading to unique physical, social and emotional effects for young people at the time of diagnosis and throughout the cancer journey.[303]

In caring for young people with cancer, akin to the comorbidities that require specific care in the older cancer population, the treatment team needs to pay careful attention to promoting normal development.[304] This requires personalised assessments and management involving a multidisciplinary, disease-specific, developmentally targeted approach that adheres to the following principles:

- understanding the developmental stages of adolescence and supporting normal adolescent health and development alongside cancer management
- understanding and supporting the rights of young people
- communication skills and information delivery that are appropriate to the young person
- meeting the needs of all involved, including the young person, their carers and their family
- working with educational institutions and workplaces
- considering survivorship and palliative care needs.

An oncology team caring for an adolescent or young adult with cancer should be able to demonstrate these specific areas of expertise:

- Be able to ensure access to expert adolescent and young adult health providers who have knowledge specific to the biomedical and psychosocial needs of the population
- understand the biology and current management of the disease in the adolescent and young adult age group
- consider participating in research and clinical trials for each patient
- engage in proactive discussion and management of fertility preservation, late effects of treatment, ongoing need for contraception, and psychosocial and psychosexual needs
- provide treatment in an environment that is friendly to adolescents and young adults.

Published in 2022, the *Optimal care pathway for adolescents and young adults with cancer, 1st edition*, provides guidance to health practitioners and service planners on optimal care for adolescents and young adults with cancer across the cancer continuum.

To view the *Optimal care pathway for adolescents and young adults with cancer*, visit the Cancer Council website <https://www.cancer.org.au/assets/pdf/optimal-care-pathway-for-adolescents-and-young-adults-with-cancer>.

People in lower socioeconomic groups

In general, people from lower socioeconomic groups are at greater risk of poor health, have higher rates of illness, disability and death, and live shorter lives than those from higher socioeconomic groups.[305] People experiencing socioeconomic disadvantage are less likely to participate in screening programs, more likely to be obese, less likely to exercise and much more likely to smoke, which are all risk factors for cancer. In 2010–2014 age-standardised cancer incidence rates were higher in the lowest socioeconomic areas compared with the highest socioeconomic areas for all cancers combined.[306]

Socioeconomic status and low health literacy are closely correlated. Therefore, effective communication with patients and carers is particularly important given the prevalence of low health literacy in Australia (estimated at 60% of Australian adults.[307]

Consideration should be taken for cancer patients experiencing socioeconomic disadvantage to reduce their risk of being underserved for healthcare.

People living with a mental illness

A diagnosis of cancer may present other challenges to people who have pre-existing chronic mental health or psychiatric concerns, resulting in exacerbation of their mental health symptoms. This may include heightened anxiety, worsening depression or thoughts of self-harm.

As poor adjustment and coping can affect treatment decisions, people who are known to have a mental health diagnosis need psychosocial assessment in the oncology setting to formulate a plan for ongoing support throughout treatment.

Psychosocial support can assist with challenges in communicating with health professionals, enhance understanding of the treatment journey, ensure capacity for consent to treatment options and improve compliance with treatment requests. A referral for psychosocial support from a health professional to the psycho-oncology team can ensure these patients are provided with targeted interventions or referrals to community-based services that may mitigate problems associated with the impacts of social isolation that frequently accompany chronic mental ill-health.

Many patients with chronic mental health problems may be well known to external service providers. Psycho-oncology health professionals can form meaningful partnerships with existing service providers to optimise patient care throughout treatment and beyond.

Drug use disorders fall within the area of mental health conditions. People who are opiate dependent may have specific and individual requirements regarding pain management and their own preference for type of opiate prescribed or used.

Lesbian, gay, bisexual, transgender, intersex, queer and asexual (LGBTIQA+) people

People who identify as sexually or gender diverse may have unique needs following a cancer diagnosis. Sexually or gender diverse identities include (but are not limited to) people who identify as lesbian, gay, bisexual or transgender, collectively 'LGBT'. There is no universally agreed upon initialism to describe this community, with other terms such as queer/questioning (Q), intersex (I), asexual (A) and pansexual (P) often included, as well as a plus symbol (+) indicating inclusivity of other identities not explicitly mentioned.

Sexual orientation and gender identity are relevant across the entire spectrum of cancer care, from prevention to survivorship and end-of-life care. LGBT people are less likely to participate in cancer screening, and some segments of the LGBT community exhibit elevated rates of specific cancer risk factors – for example, higher rates of smoking and alcohol use. Regarding treatment, there may be unique factors relevant to LGBT people that may affect decision-making. Also, the LGBT population experiences higher rates of anxiety, depression and stressful life circumstances, and may be at risk of inferior psychosocial outcomes following a cancer diagnosis. LGBT people are also more likely to be estranged from their families of origin, and for older people, less likely to have adult children who may provide support and care.

Barriers to care for LGBT people include past negative interactions with healthcare systems, experiences or fear of discrimination and harassment in healthcare settings, assumptions of cisgender/heterosexual identity, lack of recognition or exclusion of same-sex partners from care, and a lack of relevant supportive care and information resources.

To provide safe and appropriate care for LGBT people with cancer, healthcare providers should:

- display environmental cues to show an inclusive and safe setting for LGBT patients
- avoid assumptions about the sexual orientation or gender identity of patients and their partners
- facilitate positive disclosure of sexual orientation or gender identity
- include same-sex/gender partners and families of choice in care
- be aware of relevant supportive care and information resources
- provide non-judgemental, patient-centred care.

Appendix D: Complementary therapies

Complementary therapies may be used together with conventional medical treatments to support and enhance quality of life and wellbeing. They do not aim to cure the patient's cancer. Instead, they are used to help control symptoms such as pain and fatigue.[308]

The lead clinician or health professional involved in the patient's care should discuss the patient's use (or intended use) of complementary therapies not prescribed by the multidisciplinary team to assess safety and efficacy and to identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base. A transparent and honest discussion that is free from judgement should be encouraged.

While some complementary therapies are supported by strong evidence, others are not. For such therapies, the lead clinician should discuss their potential benefits and use them alongside conventional therapies.[309]

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring patients to health providers within the multidisciplinary team who have expertise in the field of complementary and alternative therapies (e.g. a clinical pharmacist, dietitian or psychologist) to assist them to reach an informed decision. Costs of such approaches should be part of the discussion with the patient and considered in the context of evidence of benefit.

The lead clinician should assure patients who use complementary therapies that they can still access a multidisciplinary team review and encourage full disclosure about therapies being used.

More information

Refer to the Clinical Oncological Society of Australia's position statement *Use of complementary and alternative medicine by cancer patients* <www.cosa.org.au/media/1133/cosa_cam-position-statement_final_new-logo.pdf>.

Appendix E: Members of the multidisciplinary team

The composition of the multidisciplinary team should encourage a multidisciplinary approach and support participation from all disciplines wherever appropriate and possible. For people with cancer from rural and remote areas, input from those with local expertise should be considered, with the acknowledgement that the disciplines represented by these patients will vary greatly.

Consideration should be given to the recommendations for multidisciplinary team composition outlined in cancer-specific optimal care pathways. To view the full clinical optimal care pathway for each cancer type, visit the Cancer Council website <www.cancer.org.au/OCP>.

Resource list

For patients, families and carers

Advance Care Planning Australia

Advance Care Planning Australia provides national advance care planning resources for individuals, families, health professional and service providers. Resources include a national advisory service, information resources, a legal forms hub and education modules.

- Telephone: 1300 208 582
- Website <www.advancecareplanning.org.au>

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre has developed information resources and events to help people move from initial treatment to post treatment and beyond, including those receiving maintenance treatments. While they do not provide clinical advice, they connect with a range of providers to enable improved care.

- Telephone: (03) 8559 6220
- Website <www.petermac.org/cancersurvivorship>

Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care has developed a resource for patients and carers explaining the coordination of care that patients should receive from their health service during cancer treatment. The resource is called *What to expect when receiving medication for cancer care* <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/what-expect-when-receiving-medication-cancer-care>.

Beyond Blue

Beyond Blue provides information about depression, anxiety and related disorders, as well as about available treatment and support services.

- Telephone: 1300 22 4636
- Website <www.beyondblue.org.au>

Carer Gateway

Australian Government program that provides free services and supports for carers.

- Telephone: 1300 422 737
- Website <www.carergateway.gov.au>

Carer Help

Online support for family members, friends or carers that provides information, helplines, information packs and videos and learning modules.

- Website <www.carerhelp.com.au>

Cancer Hub

Cancer Hub is committed to helping families dealing with a cancer diagnosis to more easily access the support they need, when they need it. Canteen, Camp Quality and Redkite have come together to offer a wide range of practical and emotional cancer support services for families facing cancer (with children aged 0–25) through this one-stop shop.

- Website <https://cancerhub.org.au/>

Cancer Council's Cancer Information and Support Service

Cancer Council 13 11 20 is a confidential telephone support service available to anyone affected by cancer. This service acts as a gateway to evidence-based documented, practical and emotional support available through Cancer Council services and other community organisations. Calls will be answered by a nurse or other oncology professional who can provide information relevant to a patient's or carer's situation. Health professionals can also access this service.

- Telephone: 13 11 20 – Monday to Friday, 9 am to 5 pm (some states have extended hours)
- Website <www.cancer.org.au/about-us/state-and-territory-councils/>

Cancer Council's Cancer Connect

Cancer Connect is a free and confidential telephone peer support service that connects someone who has cancer with a specially trained volunteer who has had a similar cancer experience.

A Connect volunteer can listen with understanding and share their experiences and ways of coping. They can provide practical information, emotional support and hope. Many people newly diagnosed with cancer find this one-to-one support very beneficial.

For more information on Cancer Connect call Cancer Council on 13 11 20.

Canteen

Canteen helps adolescents, young adults and parents to cope with cancer in their family. Canteen offers individual support services, peer support services and a youth cancer service, as well as books, resources and useful links.

- Telephone: 1800 835 932 to talk to a health professional about information and support for young people or 1800 226 833 for other enquiries
- Website <www.canteen.org.au/>

Clinical trial information

For a collection of clinical trials available in Australia see the following sources of information:

- Australian clinical trials <www.australianclinicaltrials.gov.au>
- Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>
- ClinicalTrials.gov <www.clinicaltrials.gov>.

CanEAT pathway

A guide to optimal cancer nutrition for people with cancer, carers and health professionals.

- Website <https://education.eviq.org.au/courses/supportive-care/malnutrition-in-cancer>
- Website <https://patients.cancer.nsw.gov.au/coping-with-cancer/physical-wellbeing/eating-well>

Gather my Crew

Resources to support people to coordinate practical help when someone is facing illness, injury or hardship.

- Website <www.gathermycrew.org.au>

Guides to best cancer care

The short guides help patients, carers and families understand the optimal cancer care that should be provided at each step. They include optimal timeframes within which tests or procedures should be completed, prompt lists to support patients to understand what might happen at each step of their cancer journey and to consider what questions to ask and provide information to help patients and carers communicate with health professionals.

The guides are located on an interactive web portal, with downloadable PDFs available in multiple languages.

- Website <www.cancercareguides.org.au>

Look Good, Feel Better

A free national community service program, run by the Cancer Patients Foundation, dedicated to teaching cancer patients how to manage the appearance-related side effects caused by treatment for any type of cancer.

- Telephone: 1800 650 960
- Website <https://lgfb.org.au>

Palliative Care Australia

Palliative Care Australia provides a national palliative care service directory for patients and carers to find locally available services.

- Website <https://palliativecare.org.au/>

Quitline

Quitline is a confidential, evidence-based telephone counselling service. Highly trained Quitline counsellors use behaviour change techniques and motivational interviewing over multiple calls to help people plan, make and sustain a quit attempt.

Quitline is a culturally inclusive service for all, and Aboriginal counsellors are also available. Health professionals can refer patients to Quitline online or via fax.

- Telephone: 13 7848
- Website <www.quit.org.au> or the relevant website in your state or territory.

WeCan

Australian supportive care website that supports access for people affected by cancer to information, resources and support services.

- Website <https://wecan.org.au/>

For health providers

Angel Flight

Volunteer organisation facilitating free, non-emergency flights and transfers so people living remotely across Australia can access specialist medical treatments. Referrals are facilitated by health professionals.

- Telephone: 1300 726 567
- Website <www.angelflight.org.au>

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre provides expertise in survivorship care, information, support and education. Its purpose is to support and enable optimal survivorship care.

- Telephone: (03) 8559 6220
- Website <www.petermac.org/cancersurvivorship>

Australian Commission on Safety and Quality in Healthcare

The Australian Commission on Safety and Quality in Healthcare has developed a guide for clinicians containing evidence-based strategies to support clinicians to understand and fulfil their responsibilities to cancer patients. This guide is particularly relevant to steps 3 to 6 of the optimal care pathway. The guide is titled *NSQHS Standards user guide for medication management in cancer care for clinicians* <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-medication-management-cancer-care-clinicians>.

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority.

- Website <www.cancer.org.au>

CanEAT pathway

A guide to optimal cancer nutrition for people with cancer, carers and health professionals.

- Website <https://education.eviq.org.au/courses/supportive-care/malnutrition-in-cancer>
- Website <https://patients.cancer.nsw.gov.au/coping-with-cancer/physical-wellbeing/eating-well>.

caring@home

Practical, evidence-based resources and education for health professionals to support the delivery of end-of-life care for home-based patients.

- Website <www.caringathomeproject.com.au>

Clinical Oncology Society of Australia Guidelines

Evidence-based guidelines for health professionals to inform clinical practice.

- Website <https://www.cosa.org.au/education-events/guidelines/?viewAll=true&p=1>

eviQ

A clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment.

- Website <www.eviq.org.au>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment.

- Website <www.nhmrc.gov.au>

Royal Flying Doctor Service

The Royal Flying Doctor Service provides emergency medical and primary healthcare services to those living, working and travelling in rural and remote Australia.

- Website <www.flyingdoctor.org.au/>

Glossary

advance care directive – voluntary person-led document that focus on an individual's values and preferences for future health and medical treatment decisions, preferred outcomes and care. They are completed and signed by a competent person. They are recognised by specific legislation (statutory) or common law (non-statutory). Advance care directives can also appoint the substitute decision-maker(s) who can make decisions about health or personal care on the individual's behalf if they are no longer able to make decisions themselves. Advance care directives focus on the future healthcare of a person, not on the management of his or her assets. They come into effect when an individual loses decision-making capacity.

advance care planning – the process of planning for future health and personal care, where the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate their decisions.

alternative therapies – treatments used in place of conventional medical treatment.

cancer specialist – a doctor registered with the Medical Board of Australia as a specialist (other than in general practice) and may include an individual such as a surgeon, radiation oncologist, palliative care physician, medical oncologist or internal medicine physician.

care coordinator – the health provider nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and the location and care in which care is being delivered.

complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help people deal with the side effects of cancer.

end-of-life care – includes physical, spiritual and psychosocial assessment, and care and treatment, delivered by health professionals and ancillary staff. It also includes support of families and carers and care of the patient's body after their death.

immunotherapy – a type of cancer treatment that helps the body's immune system to fight cancer. Immunotherapy can boost the immune system to work better against cancer or remove barriers to the immune system attacking the cancer.

indicator – a documentable or measurable piece of information regarding a recommendation in the optimal care pathway.

informed financial consent – the provision of cost information to patients, including notification of likely out-of-pocket expenses (gaps), by all relevant service providers, preferably in writing, before admission to hospital or treatment.[310]

lead clinician – the clinician who is nominated as being responsible for individual patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

metastatic disease – cancer that has spread from the part of the body where it started (the primary site) to other parts of the body.

multidisciplinary care – an integrated team approach to healthcare in which medical and allied health providers consider all relevant treatment options and collaboratively develop an individual treatment plan for each patient.

multidisciplinary team – comprises the core disciplines that are integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

multidisciplinary meeting (MDM) – a meeting of health professionals from one or more clinical disciplines who together make decisions about recommended treatment of patients.

optimal care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care for all people affected by cancer.

performance status – an objective measure of how well a patient can carry out activities of daily life.

primary healthcare provider – in most cases this is a general practitioner but may also include general practice nurses, community nurses, nurse practitioners, allied health professionals, midwives, pharmacists, dentists and Aboriginal health workers.

spiritual care – the aspect of humanity that refers to the way people seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

substitute decision-maker – a person permitted under the law to make decisions on behalf of someone who does not have competence or capacity.

supportive care – care and support that aims to improve the quality of life of people living with and beyond cancer and their family and carers and particular forms of care that supplement clinical treatment modalities.

survivorship care plan – a formal, written document that provides details of a person's cancer diagnosis and treatment, potential late and long-term effects arising from the cancer and its treatment, recommended follow-up, surveillance and strategies to remain well.

targeted therapy – a medicine that blocks the growth and spread of cancer by interfering with specific molecules.

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