

# Optimal care pathway for men with prostate cancer





# Optimal care pathway for men with prostate cancer

Endorsed by



**Australian Government**  
**Cancer Australia**





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# Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple health care providers and covers a range of institutions, both public and private. The Optimal Cancer Care Pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a) which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

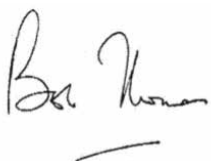
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new Optimal Cancer Care Pathways which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



Professor Robert Thomas OAM  
Chief Advisor Cancer, Department of Health and Human Services – Victoria

# Summary

Please note that not all patients will follow every step of this pathway:

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

**Prevention:** The causes of prostate cancer are not fully understood and there is currently no clear prevention strategy.

#### Early detection

Risk factors include:

- increasing age
- family history of prostate cancer
- certain dietary factors

- race (men of Caucasian background are more at risk than Asian men).

**Case finding:** Men at higher risk (based on their family history) should be counselled regarding their risk. PSA testing should be considered.

Men in good health may consider tests for early detection after discussing the risks and benefits with their primary care provider.

## Step 2

### Presentation, initial investigations and referral

#### Signs and symptoms

- The majority of men presenting with prostate cancer have no symptoms.
- Symptoms of locally advanced disease may include irritation on urination, obstructive urinary symptoms and/or blood in the urine.

#### Initial investigations include:

- PSA level
- measurement of free-to-total PSA ratio.

The significance of rising PSA (i.e. free-to-total PSA ratio), even within the age-adjusted normal range, should be recognised, as well as a PSA that is at the high end of the normal range in younger men.

Assessments by the general practitioner should be completed within one week.

**Referral:** The patient should be referred to a urologist within six to 12 weeks (without symptoms) and earlier if symptomatic.

#### Communication – lead clinician<sup>1</sup> to:

- explain to the patient/carer who they are being referred to and why
- support the patient/carer while waiting for specialist appointments.

## Step 3

### Diagnosis, staging and treatment planning

Implications of both a positive and negative biopsy result should be discussed with the patient before biopsy. A prostate biopsy should not be offered on the basis of serum PSA level alone.

#### Diagnosis and staging:

- DRE (prior to biopsy)
- prostate biopsy
- with or without prostate magnetic resonance imaging (MRI).

The use of staging investigations in men with clinically localised disease should be based on their risk of metastatic spread (Gleason score, clinical stage, PSA), and provisional treatment intent. Tests may include:

- DRE assessment
- isotope bone scans
- computed tomography (CT) scan and/or prostate MRI
- Interval reimaging (to determine the appropriate timing of androgen deprivation therapy (ADT).

**Treatment planning:** All newly diagnosed patients should be discussed by a multidisciplinary team before beginning treatment.

**Research and clinical trials:** Consider enrolment where available and appropriate.

#### Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

**Offer advice on how to access support from prostate cancer peer support groups and groups for carers; visit [www.prostate.org.au](http://www.prostate.org.au) for local area listings.**

<sup>1</sup> 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.

## Step 4

### Treatment:

Establish intent of treatment:

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

If curative treatment is considered, men should be offered an opportunity for a second opinion in order to have a balanced view about the available treatment options.

### Treatment of localised or locally advanced prostate cancer:

- **Watchful waiting:** some patients (for example, those with other health issues who are not expected to live more than 7 years) should be monitored and symptoms treated if they arise.
- **Active surveillance:** some men with low-risk prostate cancer should be regularly monitored for signs of disease progression so curative treatment can be initiated if necessary.
- **Surgery (radical prostatectomy):** may benefit some men with at least a 10-year life expectancy.

- **Radiation therapy by external beam radiotherapy (EBRT) or brachytherapy +/- ADT:** may benefit patients with at least a 10-year life expectancy.

### Treatment of advanced prostate cancer:

- **ADT** is the standard treatment. The timing of starting ADT is often related to balancing the risk of side effects against the unwanted effects of the disease.
- For patients with metastatic disease, chemotherapy, second-generation anti-androgens, bisphosphonates and RANK ligand inhibitors may be of benefit.

**Palliative care:** Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

#### Communication – lead clinician to:

- discuss treatment options with the patient/carer including the intent of treatment as well as the risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

[http://wiki.cancer.org.au/australia/Guidelines:Prostate\\_cancer/Management/Locally\\_advanced\\_and\\_metastatic](http://wiki.cancer.org.au/australia/Guidelines:Prostate_cancer/Management/Locally_advanced_and_metastatic).

## Step 5

### Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

#### Treatment summary (provided to the patient, carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided.

#### Follow-up care plan (provide a copy to patient/carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

#### Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about late effects, secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

## Step 6

### Managing recurrent, residual and metastatic disease

**Detection:** Most residual or recurrent disease will be detected by a rising PSA in asymptomatic men.

**Treatment:** Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, previous management and patient preferences.

**Palliative care:** Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

#### Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

## Step 7

### End-of-life care

**Palliative care:** Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

#### Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the patient
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.



# Summary – optimal timeframes

**Timeframes to treatment** – Timeframes should be informed by evidence based guidelines where they exist, whilst recognising that shorter timelines for appropriate consultations and treatment can reduce person's distress. The following recommended timeframes are based on expert advice from the Prostate Cancer Working Group.

Care point	Timeframe
2.2 Assessments by the General Practitioner	To be completed within 1 week
2.3 Referral to specialist	<ul style="list-style-type: none"><li>• Men without symptoms should see a specialist within 6-12 weeks of an abnormal result being identified.</li><li>• Men with symptoms should see a specialist earlier, depending on the urgency of the symptoms (including psychological distress).</li></ul>
3.1 Diagnostic work-up	Investigations to be completed within 4 weeks
4.2.1 Treatment - Surgery	Within 3 months of diagnosis
4.2.2 Treatment – Chemotherapy and other drug therapy	Within 3 months of diagnosis
4.2.2 Treatment – Radiation therapy	Timely consultation with a medical oncologist in patients who are not responding to first line therapy.

# Intent of the optimal cancer care pathway – key principles

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for people with cancer.

The pathway aligns with key service improvement priorities, including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal cancer care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality-improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal cancer care pathway.

## Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient- or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

## Safe and quality care

This is provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve the patient experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence. Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

## Multidisciplinary care

This is an integrated team approach to healthcare in which medical, nursing and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007c).

## Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool such as the *National Comprehensive Cancer Network distress thermometer and problem checklist*) of the patient and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (first three months)
- the beginning of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- survivorship
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care.

Following each assessment, potential interventions need to be discussed with the patient and carer, and a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in patients with prostate cancer that may require referral for support include:

- changes in continence
- altered sexual health or performance
- poor performance status
- breathlessness
- pain
- difficulty managing fatigue
- difficulty sleeping
- malnutrition (as identified using a validated malnutrition screening tool or presenting with weight loss)
- distress, depression or fear
- living alone or being socially isolated
- having caring responsibilities for others
- cumulative stressful life events
- existing mental health issues
- Aboriginal or Torres Strait Islander status
- being from a culturally and linguistically diverse background.

Depending on the needs of the patient, referral to an appropriate health professional(s) and/or organisation(s) should be considered including:

- a psychologist or psychiatrist
- a genetic counsellor
- community-based support services (such as those provided by state and territory Cancer Councils)
- a dietitian
- an exercise physiologist
- nurse practitioner and/or specialist nurse
- an occupational therapist
- a physiotherapist
- peer support groups (contact the Prostate Cancer Foundation of Australia on 1800 22 00 99 or Cancer Council on 13 11 20 for more information)
- a social worker
- specialist palliative care
- a speech therapist.

See the **appendix** for more information on supportive care and the specific needs of men with prostate cancer.

## Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the patient are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary team meetings, supportive care screening/assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a whole-of-system response – that is, that initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007b).

## Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families (with their consent).
- In communicating with patients, healthcare providers should:
  - listen to patients and act on the information provided by them
  - encourage expression of individual concerns, needs and emotional states
  - tailor information to meet the needs of the patient, their carer and family
  - use professionally trained interpreters when communicating with people from culturally and linguistically diverse backgrounds
- ensure the patient and/or their carer and family have the opportunity to ask questions
- ensure the patient is not the conduit of information between areas of care (it is the responsibility of providers and the healthcare system to transfer information between areas of care)
- take responsibility for communication with the patient
- respond to questions in a way the patient understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the patient a *Question prompt list* (QPL) in advance of their consultation, and recordings or written summaries of their consultations. QPL interventions are effective in improving communication, psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

## Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of treatment interventions, as well as establishing the role of psychological, supportive and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to the care of cancer patients in the future (Peppercorn et al. 2004).

# Optimal cancer care pathway

The optimal cancer care pathway outlines seven critical steps in the patient journey. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management and patient decisions, and physiological response to treatment).

The pathway describes the optimal cancer care that should be provided at each step.

## Step 1: Prevention and early detection

Eating a healthy diet, avoiding or limiting alcohol intake, regular exercise and maintaining a healthy body weight may help reduce cancer risk. This step outlines recommendations for the prevention and early detection of prostate cancer.

### 1.1 Prevention

The causes of prostate cancer are not fully understood and there is currently no clear prevention strategy.

### 1.2 Risk factors

While the causes of prostate cancer are not fully understood, there are a number of factors associated with the risk of developing the disease. These factors include:

- increasing age (Cancer Australia 2013a)
- a family history of prostate cancer (Cancer Australia 2013a)
- certain dietary factors (for example, diets high in animal fat, dairy products or calcium are associated with an increased risk) (National Cancer Institute 2014)
- race (for example, men of Caucasian background are more at risk than Asian men) (Gardiner 2010).

### 1.3 Early detection

#### 1.3.1 Screening recommendations

There is limited or conflicting evidence as to whether population screening reduces mortality from prostate cancer. Systematic reviews have concluded that population-based screening for prostate cancer using prostate-specific antigen (PSA) testing cannot be justified on the basis of current evidence (Moyer 2012).

#### 1.3.2 Case finding

Men at higher risk (based on their family history) should be proactively followed up. PSA testing for prostate cancer should be considered. Men at higher risk (based on their family history) should be proactively followed up which may include 2 yearly PSA testing from age 45-69 years (NHMRC 2016).

If there is a strong or known genetic background (for example, BRCA2) or a strong family history of prostate, breast or ovarian cancer, consider referral to a familial cancer centre.

Men in good health may consider tests for early detection of prostate cancer after discussing the risks and benefits with their primary care provider. A summary of the evidence on the benefits and harms of PSA testing for prostate cancer in asymptomatic men can be found at <[https://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/men4d\\_psa\\_testing\\_asymptomatic\\_men\\_140304.pdf](https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/men4d_psa_testing_asymptomatic_men_140304.pdf)>. For detailed clinical practice guidelines on PSA Testing and Early Management of Test-Detected Prostate Cancer refer to: <[http://wiki.cancer.org.au/australia/Guidelines:PSA\\_Testing](http://wiki.cancer.org.au/australia/Guidelines:PSA_Testing)>.

## Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral. The types of investigation undertaken by the general or primary practitioner depend on many factors, including access to diagnostic tests and medical specialists and patient preferences.

### 2.1 Signs and symptoms

The majority of men presenting with prostate cancer have no symptoms.

A minority of men present with locally advanced disease. Symptoms and signs of locally advanced disease may include obstructive or irritative urinary symptoms or blood in the urine.

Only a small percentage of men present with metastatic disease; symptoms may include back pain, bone pain, weight loss and neurological symptoms, and/or symptoms of the primary cancer.

### 2.2 Assessments by the general or primary medical practitioner

Investigations prior to referral should include PSA level (Frydenberg 2007), recognising the effects of age on normal reference ranges.

An abnormal result should be discussed face to face with the patient, and information provided.

The significance of rising PSA, even within the age-adjusted normal range in an individual man, should be recognised, as well as a PSA that is at the high end of the normal range in younger men. Measurement of free-to-total PSA ratio may be helpful in assessing the clinical significance of an elevated PSA.

#### Timeframe for completing investigations

Timeframes for completing investigations should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The expert opinion of the Prostate Cancer Working Group<sup>1</sup> is for assessments by the general practitioner to be completed within one week.

### 2.3 Referral

The patient should be referred to a urologist (Fellow of the Royal Australasian College of Surgeons (FRACS) or equivalent) who is affiliated with or has access to a multidisciplinary team (and multidisciplinary team meetings).

Referral for suspected prostate cancer should incorporate appropriate documentation sent with the patient including:

- a letter that includes important psychosocial history and relevant past history, family history, current medications and allergies
- results of current clinical investigations and abnormal results (DRE and/or PSA)
- results of all prior relevant investigations
- notification if an interpreter service is required.

If access is via online referral, a lack of a hard copy (of results) should not delay referral.

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<sup>1</sup> The multidisciplinary experts who participated in a clinical workshop to develop content for the prostate cancer optimal care pathway are listed in the acknowledgements list.



### Timeframe for referral to a specialist

Timeframes for referral should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the Prostate Cancer Working Group:

- Men without symptoms should see a specialist within six to 12 weeks of an abnormal result being identified.
- Men with symptoms should see a specialist earlier, depending on the urgency of the symptoms (including psychological distress).

The supportive and liaison role of the GP and practice team in this process is critical.

## 2.4 Support and communication

### 2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified supportive care needs of an individual, their carer and family; referral should be as required.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- treatment for physical (lower urinary tract) symptoms including difficulty starting to urinate, frequent urination (particularly at night), difficulty stopping the flow of urine and poor urine flow
- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties
- guidance about financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients and caring arrangements for other family members)
- appropriate information for men from culturally and linguistically diverse backgrounds.

### 2.4.2 Communication with the patient, carer and family

Effective communication is essential at every step of the care pathway. Effective communication with the patient and carer is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- provide the patient with information that clearly describes which specialist(s) they are being referred to, the reason for referral and expected timeframes for specialist appointments
- support the patient while waiting for the specialist appointment.

## Step 3: Diagnosis, staging and treatment planning

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

### 3.1 Diagnostic workup

To help patients decide whether to have a prostate biopsy, discuss with them their PSA level, DRE findings (including an estimate of prostate size) and comorbidities, together with their risk factors (including family history, increasing age and family origin) and any history of a previous negative prostate biopsy. Do not automatically offer a prostate biopsy on the basis of serum PSA level alone (NICE 2014).

The following tests may be performed to confirm a diagnosis:

- DRE (prior to biopsy)
- prostate biopsy
- in some circumstances, imaging may have a role in diagnosis and risk assessment; currently magnetic resonance imaging (MRI) is the most promising modality and should be performed by a radiologist (FRANZCR or equivalent) with adequate training and experience and with MRI-specific accreditation.

All biopsies should be completed by an adequately trained urologist or radiologist under transrectal ultrasound, with biopsy needles placed either transrectally or transperineally.

Implications of both a positive and negative biopsy result should be discussed with the patient before biopsy.

The specimen needs to be reviewed by an experienced uropathologist if there are uncertainties about diagnosis.

There should be standardised protocols for:

- minimum number of cores in the biopsy sample
- interpretation of the specimens
- follow-up/re-biopsy of equivocal findings.

The lead clinician should review the risk factors of all men who have had a negative first prostate biopsy, and discuss with the man that:

- there is still a risk that prostate cancer is present
- the risk is slightly higher if any of the following risk factors are present
  - the biopsy showed atypical small acinar proliferation (ASAP)
  - abnormal DRE (NICE 2014).

### Timeframe for completing investigations

Timeframes for completing investigations should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The expert opinion of the Prostate Cancer Working Group is for investigations to be completed within four weeks.

## 3.2 Staging

Staging, including DRE assessment and imaging (computed tomography (CT) or bone scan as appropriate), is important in treatment planning.

The clinical stage of the tumour based on DRE assessment should be recorded in the medical record.

Determine the provisional treatment intent (curative or non-curative) before decisions on imaging are made (NICE 2014). Do not routinely recommend imaging to men who are not candidates for curative treatment (NICE 2014).

A bone scan or CT scan should not be undertaken for men with a PSA < 10 ng/mL or a Gleason Score < 7, unless otherwise clinically indicated (Amis et al. 2000; Greene et al. 2009; Heidenreich et al. 2008; Mohler et al. 2010).

Recommend isotope bone scans when hormonal therapy is being deferred through watchful waiting to asymptomatic men (with incurable disease) and who are at high risk of developing bone complications (NICE 2014). Interval reimaging may have a role in determining the appropriate timing of androgen deprivation therapy.

Consider multiparametric MRI, or CT if MRI is contraindicated, for men with histologically proven prostate cancer if knowledge of the T or N stage could affect management (NICE 2014).

Pathological staging occurs after surgery and synoptic reporting is encouraged.

## 3.3 Treatment planning

### 3.3.1 Responsibilities of the multidisciplinary team

These are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the multidisciplinary meeting
- circulate the agreed treatment plan to all relevant team members, including the general practitioner.

### 3.3.2 Responsibilities of individual team members

The general or primary medical practitioner who made the referral is responsible for the patient until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment, coordination and continuity of care, as well as providing information and support to the patient, their carer and family.

The care coordinator is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team.

### 3.3.3 Members of the multidisciplinary team for prostate cancer

The multidisciplinary team should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some patients (Department of Health 2007c).

Team members may include a:

- care coordinator (as determined by multidisciplinary team members)\*
- medical oncologist\*
- nurse (with appropriate expertise)\*
- pathologist\*
- radiation oncologist\*
- radiologist/imaging specialists\*
- urologist\*
- clinical trials coordinator
- continence practitioner
- dietician
- endocrinologist
- exercise physiologist
- general practitioner
- nuclear medicine physician
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- psychologist
- psychiatrist
- social worker

\* Core members of the multidisciplinary team are expected to attend most multidisciplinary team meetings either in person or remotely.

### **3.3.4 The optimal timing for multidisciplinary team planning**

Ideally, all newly diagnosed patients should be discussed at a multidisciplinary team meeting before beginning treatment. The level of discussion may vary depending on both the clinical and psychosocial factors.

There may also need to be a review of existing treatment plans for patients who have been discussed previously.

Results of all relevant tests and imaging should be available for the multidisciplinary team discussion. Information about the patient's concerns, preferences and social circumstances should also be presented at the meeting by the care coordinator or lead clinician (Department of Health 2007c).

### **3.4 Research and clinical trials**

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- 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. For more information visit <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

### **3.5 Prehabilitation, support and communication**

#### **3.5.1 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, chemotherapy, immunotherapy and radiation therapy.

Evidence indicates that prehabilitating newly diagnosed cancer patients prior to starting treatment can be beneficial. This may include conducting a physical and psychological assessment to establish a baseline function level, early referral to a continence physiotherapist, and identifying impairments and providing targeted interventions to improve the patient's health, thereby reducing the incidence and severity of current and future impairments related to cancer and its treatment (Silver & Baima 2013).

Medications should be reviewed at this point to ensure optimisation and to improve adherence to medicines used for comorbid conditions.

### 3.5.2 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network distress thermometer and problem checklist), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- treatment for physical symptoms including pain, fatigue, incontinence, urinary retention or voiding difficulties
- sexual function/dysfunction
- fertility
- help with psychological and emotional distress while adjusting to the diagnosis, treatment phobias, existential concerns, difficulties making treatment decisions, anxiety/depression, body issues, sexual dysfunction and interpersonal problems
- guidance for financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients and caring arrangements for other family members)
- appropriate information for men from culturally and linguistically diverse backgrounds.

### 3.5.3 Communication with the patient

The lead clinician should:

- offer advice to patients and carers on the benefits of and how to access support from prostate cancer peer support groups, groups for carers, and special interest groups
- offer advice on how to access support from websites and community and national cancer services
- establish if the patient has a regular or preferred general practitioner
- provide the patient and carer with information, support and adequate time to decide whether or not they wish to undergo prostate biopsy including an explanation of the risks (not forgetting the increased chance of having to live with the diagnosis of clinically insignificant prostate cancer) and benefits of prostate biopsy
- use a professionally trained interpreter when communicating with men from culturally or linguistically diverse backgrounds (NICE 2004)
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss benefits of multidisciplinary care and make the patient aware their health information will be available to the team for the discussion at the multidisciplinary team meeting
- if the patient is a smoker, provide information about smoking cessation.

### 3.5.4 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the general practitioner regarding the treatment plan and recommendations from multidisciplinary team meetings and notify the general practitioner if the patient does not attend
- gather information from the general practitioner, including their perspective on the patient (psychological issues, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the general practitioner to participate in multidisciplinary team meetings (consider using video or teleconferencing).

## Step 4: Treatment

Step 4 outlines the treatment options for prostate cancer. For detailed information on treatment options and side effects of treatment refer to Cancer Council Australia's (2010) Clinical guidelines: Management of locally advanced and metastatic prostate cancer at <[http://wiki.cancer.org.au/australia/Guidelines:Prostate\\_cancer/Management/Locally\\_advanced\\_and\\_metastatic](http://wiki.cancer.org.au/australia/Guidelines:Prostate_cancer/Management/Locally_advanced_and_metastatic)>.

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

The lead clinician should discuss treatment intent and prognosis with the patient and carer prior to beginning treatment.

If curative treatment is considered, men should be offered an opportunity for a second opinion from a radiation oncologist and a urologist in order to have a balanced view about the available treatment options.

If appropriate, advance care planning should be initiated with patients at this stage. Advance care planning can provide multiple benefits such as ensuring a person's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

### 4.2 Treatment options

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient.

#### 4.2.1 Treatment of localised or locally advanced prostate cancer

This may involve:

- watchful waiting
- active surveillance
- surgery (radical prostatectomy)
- radiation therapy by external beam radiotherapy (ERBT) or brachytherapy (Gardiner 2010).

#### Watchful waiting

Some patients, for example those with other health issues who are not expected to live more than seven years (NHMRC 2016), should be regularly monitored and symptoms treated if they arise. If the cancer progresses, they should receive palliative treatment rather than a treatment with a curative intent such as surgery or radiotherapy.

#### Active surveillance

The majority of men with low-risk prostate cancer will not die from their cancer. Men with low-risk prostate cancer should be offered the opportunity to be regularly monitored for signs of disease progression so curative treatment can be initiated if necessary (Gardiner 2010).

## **Surgery**

Patients who may benefit from radical prostatectomy include those with localised or locally advanced prostate cancer with at least a 10-year life expectancy, who have been assessed as suitable by a multidisciplinary team.

### **Timeframe for commencing treatment**

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The expert opinion of the Prostate Cancer Working Group is for treatment to commence within three months of diagnosis.

### **Training, experience and treatment centre characteristics**

The training and experience required of the surgeon are as follows:

- surgeon (FRACS or equivalent) with adequate training and experience in urological surgery and institutional cross-credentialling and agreed scope of practice within this area (ACSQHC 2004).

Hospital or treatment unit characteristics for providing safe and quality care include:

- an intensive care unit
- 24-hour medical staff availability
- 24-hour operating room access
- pathology
- a diagnostic imaging facility
- specialised urology, continence nursing and physiotherapy support
- support for managing common complications of surgery such as treating incontinence with artificial urinary sphincters or slings.

### **Radiation therapy (by ERBT or brachytherapy)**

Patients who may benefit from radiation therapy include:

- those with localised/locally advanced prostate cancer who have at least a 10-year life expectancy and have been assessed as suitable by a multidisciplinary team
- those with locally advanced disease who may benefit from multimodality therapy.

Some patients will receive neoadjuvant/adjuvant hormones with radiotherapy.

### **Timeframe for commencing treatment**

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The expert opinion of the Prostate Cancer Working Group is for treatment to commence within three months of diagnosis.



### Training, experience and treatment centre characteristics

Training and experience required of the appropriate specialist(s):

- radiation oncologist (FRANZCR or equivalent) with adequate training and experience and institutional cross-credentialing and agreed scope of practice in prostate cancer (ACSQHC 2004).

Hospital or treatment unit characteristics for providing safe and quality care include:

- specific trained brachytherapy staff (plus urologist) (for those sites delivering brachytherapy)
- access to allied health
- access to CT scanning for simulation and planning
- trained radiotherapy nurses, physicists and therapists.

#### 4.2.2 Treatment of advanced prostate cancer

##### Androgen deprivation therapy

The standard treatment for men with advanced prostate cancer is androgen deprivation therapy (ADT). Because of the significant side effects of ADT, many of which increase over time, and since there is little survival benefit from starting early rather than later, the timing of starting ADT is often related to balancing the risk of side effects against the unwanted effects of the disease (Gardiner 2010).

Clinicians prescribing ADT (including general practitioners and clinical practice nurses) should be trained in the administration of, and experienced in the long-term side effects of, hormone treatment. Side effects should be **monitored through regular review with the patient**.

##### Chemotherapy and other drug therapy

For patients with metastatic disease, chemotherapy, second-generation anti-androgens, bisphosphonates and RANK ligand inhibitors may be of benefit. Consideration should be given to the metabolic, cardiovascular and bone health of the patient and preventative measures instituted as appropriate.

##### Timeframe for commencing treatment

Timeframes for starting treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The expert opinion of the Prostate Cancer Working Group is for timely consultation with a medical oncologist in patients who are not responding to first-line therapy.

### Training, experience and treatment centre characteristics

The following training and experience is required of the appropriate specialist(s):

- Medical oncologists (RACP or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy administration and handling and disposal of cytotoxic waste.
- Chemotherapy should be prepared by a pharmacist with adequate training in chemotherapy medication, including dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training and experience with credentialling and agreed scope of practice within this area under the guidance of a medical oncologist. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.
- When hormone therapy is indicated, it can be initiated by any lead clinician involved with the patient, and treatment can be continued by and shared with the general practitioner.

Hospital or treatment unit characteristics for providing safe and quality care include:

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols are available to deliver treatment safely (including dealing with extravasation of drugs)
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

#### 4.2.3 Palliative treatments

Treatments for symptom palliation include analgesics and other supportive care measures, chemotherapy, palliative radiotherapy, surgery (palliative transurethral resection) and the use of bisphosphonates.

Further information about palliative treatments is available at <http://www.pcfa.org.au/awareness/advanced-prostate-cancer/download-information/>.

### 4.3 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 (Haines 2011; Temel et al. 2010). This is particularly true for poor-prognosis cancers (Temel et al. 2010).

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

Men with metastatic prostate cancer should be referred for specialist palliative care or a coordinated palliative care approach to assist in advance care planning. There is evidence that interdisciplinary palliative care can improve symptom management and enhance the wellbeing of men with metastatic prostate cancer (Australian Cancer Network 2010).

#### Further information

Refer patients and carers to Palliative Care Australia. See <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

### 4.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- For more information visit <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.
- Pathfinder Prostate Cancer Research Register is a national online register for people interested in participating in research into improving the health and lives of people post-prostate cancer treatment. For more information visit <<https://pathfinderregister.com.au>>.

### 4.5 Complementary or alternative therapies

The lead clinician should discuss the patient's use (or intended use) of complementary or alternative therapies not prescribed by the multidisciplinary team 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.

Many alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases and the treating team should be open to discussing potential benefits for the individual.

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the multidisciplinary team who have knowledge of complementary and alternative therapies (such as a clinical pharmacist, dietitian or psychologist) to help them reach an informed decision.

The lead clinician should assure patients who use complementary or alternative therapies that they can still access multidisciplinary team reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 2010).

## Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>>.
- See the Clinical Oncology Society of Australia's position statement at <[www.cosa.org.au/publications/position-statements.aspx](http://www.cosa.org.au/publications/position-statements.aspx)>.

## 4.6 Support and communication

### 4.6.1 Supportive care

Screening with a validated screening tool (such as the *National Comprehensive Cancer Network distress thermometer and problem checklist*), assessing and referring to appropriate health professionals and/or organisations is required to meet the identified needs of an individual, their carers and family.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- physical symptoms including pain, fatigue, incontinence, urinary retention or voiding difficulties, bladder outlet obstruction and altered bowel function
- erectile dysfunction, ejaculation dysfunction and impotence as a result of treatment will require referral to a medical specialist and clinicians skilled in counselling in this area
- rectal complications, which may require involvement of a continence nurse
- weight gain and fluid retention, and loss of muscle mass as a result of hormone therapy, which may require referral to a dietitian for review and referral to an exercise physiologist
- decline in mobility and/or functional status as a result of treatment
- assistance with managing complex medication regimens, multiple medications, assessment of side-effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required
- emotional and psychological issues including, but not limited to, 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
- financial issues related to loss of income and additional expenses as a result of illness and/or treatment
- legal issues (including advance care planning, appointing a power of attorney and completing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

#### **4.6.2 Communication with the patient, carer and family**

The lead clinician should:

- offer advice to patients and carers on the benefits of and how to access support from prostate cancer peer support groups, groups for carers and special interest groups
- offer advice on how to access support from websites and community and national cancer services
- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes – provide a written plan
- provide the patient and carer with information on the possible side effects of treatment, self-management strategies and emergency contacts
- initiate a discussion regarding advance care planning with the patient and carer.

#### **4.6.3 Communication with the general practitioner**

The lead clinician should:

- discuss with the general practitioner their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding
  - 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 and/or clinical trials
  - changes in treatment or medications
  - recommendations from the multidisciplinary team.

## Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completing initial treatment, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the multidisciplinary team. Transition from acute to primary or community care will vary depending on the type and stage of cancer and needs to be planned. In some cases, people will require ongoing, hospital-based care.

### 5.1 Survivorship

In the past two decades, the number of people surviving cancer has increased. International research shows there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors experience particular issues, often different from people having active treatment for cancer.

Many cancer survivors experience persisting side effects at the end of their treatment. Emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Late effects may occur months or years later and are dependent on the type of cancer treatment. Survivors may experience altered relationships and may encounter practical issues including difficulties with return to work or study, and financial hardship.

Survivors generally need to see a doctor for regular follow-up, often for five or more years after cancer treatment finishes. The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes four essential components of survivorship care (Hewitt et al. 2006):

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer spread, recurrence or second cancers; and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including management of symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient's needs are met.

All patients should be educated in managing their own health needs (NCSI 2015).

### 5.2 Post-treatment care planning

#### 5.2.1 Treatment summary

After initial treatment, the patient, carer (as appropriate) and general practitioner should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- the type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

### 5.2.2 Follow-up care

The frequency and duration of surveillance should reflect the risk of recurrence and ongoing side effect management. Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines. Not all men will require ongoing tests or clinical review.

Responsibility for follow-up care should be agreed between the lead clinician, the general practitioner, relevant members of the multidisciplinary team and the patient, with an agreed plan documented that outlines:

- what medical follow-up is required (surveillance for cancer spread, recurrence or secondary cancers and screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of cancer and cancer treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence.

In particular circumstances, follow-up care can safely and effectively be provided:

- in the primary care setting
- by other suitably trained staff
- in a non-face-to-face setting (for example, by telehealth).

Access to a range of health professions may be required including specialist urology nursing (such as for continence concerns), physiotherapy, occupational therapy, social work, dietetics, clinical psychology and palliative care.

### 5.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- For more information visit <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.
- See also the Pathfinder Prostate Cancer Research Register at <<https://pathfinderregister.com.au>>.

## 5.4 Support and communication

### 5.4.1 Supportive care

Screening using a validated screening tool (such as the *National Comprehensive Cancer Network distress thermometer and problem checklist*), assessment and referral to appropriate health professionals and community-based support services is required to meet the needs of individual patients, their families and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- physical symptoms including incontinence, urinary retention or voiding difficulties and bladder outlet obstruction, pain and fatigue
- erectile dysfunction, ejaculation dysfunction and impotence as a result of treatment, which will require referral to a medical specialist and clinicians skilled in counselling in this area
- rectal complications, which may require involvement of a continence nurse and stomal therapist
- weight gain and fluid retention as a result of hormone therapy, which may require referral to a dietitian for review
- decline in mobility and/or functional status as a result of treatment
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns
- a need for increased community supports as patients recover from treatment
- financial and employment issues (such as loss of income and assistance with returning to work and the cost of treatment, travel and accommodation)
- legal issues (including advance care planning, appointing a power of attorney and completing a will)
- the need for appropriate information for men from culturally and linguistically diverse backgrounds.

### 5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway, from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include urinary and sexual function, cognitive changes, managing cancer-related fatigue, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.



### **5.4.3 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 (Haines 2011; Temel et al. 2010). This is particularly true for poor-prognosis cancers (Temel et al. 2010).

Men with metastatic prostate cancer should be referred for specialist palliative care or a coordinated palliative care approach be used to assist in advance care planning. There is evidence that interdisciplinary palliative care can improve symptom management and enhance the wellbeing of men with metastatic prostate cancer (Australian Cancer Network 2010).

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on need, not prognosis.

Patients should be encouraged to develop an advance care plan (AHMAC 2011).

Ensure all carers and families receive information, support and guidance about their role regarding their needs and wishes (Palliative Care Australia 2005).

#### **Further information**

- Refer patients and carers to Palliative Care Australia. See <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

### **5.4.4 Communication with the patient, carer and family**

The lead clinician should:

- offer advice to patients and carers on the benefits of, and how to access, support from prostate cancer peer support groups, groups for carers and special interest groups
- explain the treatment summary and follow-up care plan
- provide information about the signs and symptoms of recurrent disease
- provide information about secondary prevention and healthy living.

### **5.4.5 Communication with the general practitioner**

The lead clinician should ensure regular, timely, two-way communication with the general practitioner regarding:

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the patient's progress
- recommendations from the multidisciplinary team
- any shared care arrangements
- a process for rapid re-entry to medical services for patients with suspected recurrence.

## Step 6: Managing recurrent, residual or metastatic disease

Step 6 is concerned with managing recurrent or residual local and metastatic disease.

### 6.1 Signs and symptoms of recurrent, residual or metastatic disease

The majority of prostate cancer recurrences are detected by a rising PSA in an asymptomatic man. Some men will present with symptoms of recurrent disease (pain, loss of energy, weight loss). Some cases of recurrent disease will be detected by routine follow-up in a patient who is asymptomatic.

### 6.2 Multidisciplinary team

There should be timely referral to the original multidisciplinary team (where possible), with referral on to a specialist centre for recurrent disease as appropriate.

### 6.3 Treatment

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

Treatment may include surgery, radiotherapy, ADT, chemotherapy and/or bisphosphonates and RANK ligand inhibitors.

Treatment may also include involvement in a clinical trial.

Discussion of treatment may include advance care planning and referral to other health professionals.

### 6.4 Palliative care

Men with metastatic prostate cancer should be referred for specialist palliative care or a coordinated palliative care approach to assist in advance care planning. There is evidence that interdisciplinary palliative care can improve symptom management and enhance the wellbeing of men with metastatic prostate cancer (Australian Cancer Network 2010).

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on need, not prognosis.

Patients should be encouraged to develop an advance care plan (AHMAC 2011).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Begin discussions with the patient and carer about their preferred place of death.

#### Further information

Refer patients and carers to Palliative Care Australia. See <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

### 6.5 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

## 6.6 Support and communication

### 6.6.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of an individual, their carer and family.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- physical symptoms including pain, fatigue, incontinence, urinary retention or voiding difficulties and bladder outlet obstruction
- erectile dysfunction, ejaculation dysfunction and impotence as a result of treatment, which will require referral to a medical specialist and clinicians skilled in counselling in this area
- rectal complications, which may require involvement of a continence nurse and stomal therapist
- weight gain as a result of hormone therapy, which may require referral to a dietitian, physiotherapist and exercise physiologist for review
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- decline in mobility and/or functional status as a result of recurrent disease and treatments
- increased practical and emotional support needs for families and carers, including help with family communication, teamwork and care coordination where these prove difficult for families
- emotional and psychological distress resulting from fear of death/dying, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns
- financial issues as a result of disease recurrence (such as early access to superannuation and insurance)
- legal issues (such as advance care planning, appointing medical and financial powers of attorney and developing a will)
- the need for appropriate information for men from culturally and linguistically diverse backgrounds.

### 6.6.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care. Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, urinary/sexual function, improving physical endurance, achieving independence in daily tasks, returning to work and leisure and ongoing adjustment to disease and its sequelae.

### 6.6.3 Communication with the patient, carer and family

The lead clinician should ensure there is adequate discussion with the patient and carer about the expected disease course and recommended treatment, including the intent of treatment and possible outcomes, likely adverse effects and supportive care options available.

## Step 7: End-of-life care

End-of-life care is appropriate when the patient's symptoms are increasing and functional status is declining. Step 7 is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach the end of life, as well as the needs of their family and carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the patient and their family.

### 7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist backup, inpatient palliative care bed access as required, social work and bereavement counselling) with general practitioner engagement.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The palliative care team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or other spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).

The team might also recommend accessing:

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

Consideration of the patient's appropriate place of care and preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

#### Further information

Refer patients and carers to Palliative Care Australia. See <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

### 7.2 Research and clinical trials

Participation in research and clinical trials should be encouraged where available and appropriate.

For more information visit <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

## 7.3 Support and communication

### 7.3.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of an individual, their carer and family.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- physical symptoms including pain, fatigue, incontinence, urinary retention or voiding difficulties and bladder outlet obstruction
- decline in mobility and/or functional status impacting on discharge destination
- emotional and psychological distress from anticipatory grief, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support for the patient as well as their carer and family
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the patient
- legal issues relevant to men with advanced disease such as accessing superannuation early, advance care planning, powers of attorney and completing a will
- information for patients and families about arranging a funeral
- specific spiritual needs that may benefit from the involvement of pastoral care
- bereavement support for family and friends
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs.

### 7.3.2 Communication with the patient, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the patient and carer with the contact details of a palliative care service.

### 7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning and transition planning to ensure the patient's needs and goals are addressed in the appropriate environment. The patient's general practitioner should be kept fully informed and involved in major developments in the patient's illness trajectory.

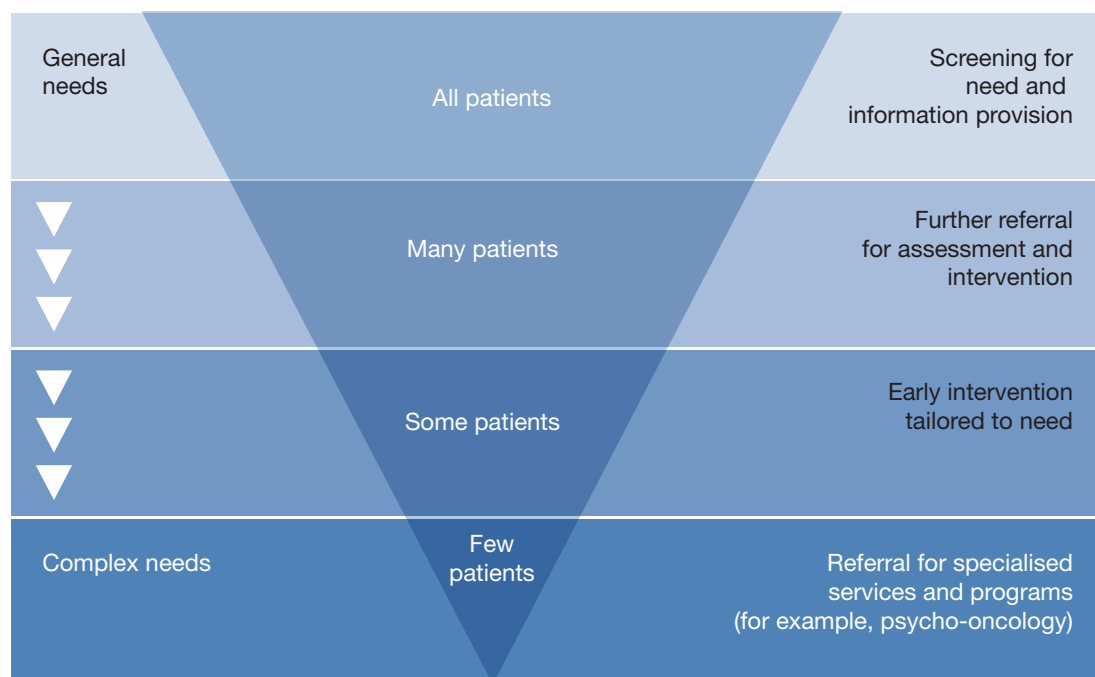
# Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and their family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet patients' supportive care needs.

**Figure 1: The tiered approach**



While all patients require general information, only a few will require specialised intervention. Common indicators in patients with prostate cancer who may require referral to appropriate health professionals and/or organisations include the following:

### **Physical needs**

- Incontinence, urinary retention or voiding difficulties and bladder outlet obstruction are frequently reported symptoms (NBCC & NCCI 2003) for men with prostate cancer and may require involvement of a urology/continence nurse specialist and a urologist.
- Erectile dysfunction and ejaculation dysfunction and impotence (from partial to complete) require sensitive discussion (NBCC & NCCI 2003). Referral to a medical specialist and clinicians skilled in teaching/counselling in this area may be required.
- Rectal complications, including faecal incontinence and radiation proctitis, may require involvement of a continence nurse specialist, stomal therapist and medical specialist (NICE 2002).
- Patients should be informed about the possibility of 'hot flushes' as a result of hormone therapy. Advice on reducing alcohol intake, avoiding hot drinks, undertaking regular exercise and relaxation may be helpful.
- Because osteoporosis can be a delayed outcome of hormone therapy, regular monitoring by a medical practitioner and a baseline bone mineral density may be required (Spigelman & McGrath 2002).
- Other metabolic and cardiovascular complications resulting from hormone therapy should also be regularly monitored by a medical practitioner.
- Weight gain and fluid retention as a result of hormone therapy may require referral to a dietitian and review by the medical practitioner.
- Referral to a pharmacist may be useful for men managing multiple medications.

## Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, gay, bisexual, transgender and intersex (LGBTI) communities) a cancer diagnosis can come with additional psychosocial complexities. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some men may have disabling symptoms and may benefit from referral to psychology services.
- Cognitive changes as a result of androgen deprivation therapy (such as altered memory, attention and concentration) can occur.
- Distress and depression can be just as common in carers and family members including children.
- Consider a referral to a psychologist, psychiatrist or social worker if the patient is:
  - displaying emotional cues such as tearfulness, distress, avoidance or withdrawal
  - preoccupied with or dwelling on thoughts about cancer and death
  - displaying fears about the treatment process and/or the changed goals of their treatment
  - worried 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 impact that prostate cancer is having on their life and the disruption to their life plans
  - struggling with communicating to 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 with quitting smoking or other drug and alcohol use
  - having difficulties transitioning to palliative care.



### **Body image**

- Body image in general and issues about feelings of masculinity and concerns about developing breasts as a result of hormone therapy may be an issue. Providing patients with tailored, accurate information prior to treatment, facilitating patient decision making about appearance-altering treatment, and meeting others with similar personal experiences may assist some men. Support and counselling by a specialist psychologist, psychiatrist or social worker may be required (NBCC & NCCI 2003).

### **Fertility preservation**

- Evidence is limited, but fertility declines when erectile function and libido are affected. Referral to counselling specialists for sperm banking may be required (NBCC & NCCI 2003).

### **Social/practical needs**

- The additional costs of continence and erectile dysfunction aids may have a financial impact. Referral to a social worker should be considered.
- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.
- Many men experience changed relationships, difficulties returning to work or study, and financial impacts. Consider referral to an occupational therapist or social worker for assistance.

### **Spiritual needs**

- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

## Populations with special needs

### Elderly people with cancer

Planning and delivering appropriate cancer care for elderly people presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia recommended that people over the age of 70 undergo some form of geriatric assessment, in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

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

### Culturally and linguistically diverse (CALD) communities

For people from CALD backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In some 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 those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are 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 born overseas and particular attention should be paid to supporting these patients (Department of Health 2009).

## **Aboriginal and Torres Strait Islander communities**

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survival also significantly decreases as remoteness increases, unlike the survivorship rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013b). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013b):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase understanding of barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve the capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our understanding of care gaps through data monitoring and targeted priority research.

# Resource list

## For patients, families and carers

### Andrology Australia

Information on male reproductive health

- Telephone: 1300 303 878
- <[www.andrologyaustralia.org](http://www.andrologyaustralia.org)>

### Australian Cancer Survivorship Centre

Has general and tumour-specific information, primarily focused on the post-treatment survivorship phase

- Telephone: (03) 9656 5207
- <[www.petermac.org/cancersurvivorship](http://www.petermac.org/cancersurvivorship)>

### beyondblue

Information on depression, anxiety and related disorders, available treatment and support services

- Telephone: 1300 22 4636
- <[www.beyondblue.org.au](http://www.beyondblue.org.au)>

### Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers

- Telephone: 1800 624 973
- <[www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)>

### Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer that provides information on treatment, cancer support groups and other community resources

- Telephone: 13 11 20 (Monday to Friday, 8.30 am – 5.30 pm)
- <[www.cancervic.org.au](http://www.cancervic.org.au)>

### Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness, how to care and finding services

- Telephone: (08) 7221 8233
- <[www.caresearch.com.au](http://www.caresearch.com.au)>

### Continence Foundation of Australia

Provides advocacy and support for those affected by bladder or bowel control issues

- Telephone: 1800 33 00 66
- <[www.continence.org.au](http://www.continence.org.au)>

### Pathfinder – Prostate Cancer Research Register

A national online register for participating in research into improving the health and lives of people post-prostate cancer treatment.

- <<https://pathfinderregister.com.au>>

### Prostate Cancer Foundation of Australia

Information about prostate cancer and where to go for support and help, including state and territory support groups

- Telephone: 1800 22 00 99
- <[www.prostate.org.au](http://www.prostate.org.au)>

### Prostmate

Provides personalised, specialist support online

- <[www.prostmate.org.au](http://www.prostmate.org.au)>

## For health professionals

### Andrology Australia

Works with health experts and education to develop collaborative strategies to raise the awareness of male reproductive health disorders

- <[www.andrologyaustralia.org](http://www.andrologyaustralia.org)>

### Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants

- <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>

### Cancer Australia

Information on clinical practice guidelines, reports, fact sheets, DVDs, posters and pamphlets

- <[www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)>

**Cancer Council Australia**

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

- <[www.cancer.org.au](http://www.cancer.org.au)>

**EviQ**

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

- <[www.eviq.org.au](http://www.eviq.org.au)>

**National Health and Medical Research Council**

Information on clinical practice guidelines, cancer prevention and treatment

- <[www.nhmrc.gov.au](http://www.nhmrc.gov.au)>

# Glossary

**Advance care planning** – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

**Alternative therapies** – treatments that are used in place of conventional medical treatment, often in the hope that they will provide a cure.

**Care coordinator** – the health professional 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 where care is primarily located.

**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** – a distinct phase of palliative care that is appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

**General/primary medical practitioner** – the practitioner to whom the patient first presents with symptoms; this may be the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

**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.

**Multidisciplinary care** – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each patient (Department of Health 2007c).

**Multidisciplinary team** – comprises the core disciplines 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.

**Optimal cancer 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.

**Palliative care** – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

**Patient management framework** – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal cancer care pathways are updated versions of these models.

**Prehabilitation** – one or more interventions undertaken with a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the patient undergoes treatment and beyond.

**Primary specialist** – the person who makes the referral to the multidisciplinary team (such as specialist physician, surgeon, oncologist or palliative care specialist). This person will also make referrals for treatment and will be responsible for overseeing follow-up care.

**Rehabilitation** – comprises multidisciplinary efforts to allow the patient to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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## **Governance – project steering committee representation**

Ballarat Health Services  
Cancer Australia  
Cancer Council Victoria Strategy and Support  
Consumer representatives  
Department of Health, Victoria, Cancer Strategy and Development  
Grampians Integrated Cancer Service  
Monash University  
North Eastern Melbourne Integrated Cancer Service  
Peter MacCallum Cancer Centre  
Royal Hobart Hospital  
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## **Medical colleges and peak organisations invited to provide feedback**

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Australian Association of Nuclear Medicine Specialists  
Australian and New Zealand Society of Palliative Care  
Australian Chapter of Palliative Medicine, Royal Australasian College of Physicians  
Australian College of Nursing  
Australian Institute of Radiography  
Australian Medical Association  
Interventional Radiology Society of Australasia  
Medical Oncology Group of Australia  
Royal Australasian College of Physicians  
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Royal Australian College of General Practitioners

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