

# Optimal cancer care pathway for people with melanoma





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**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.

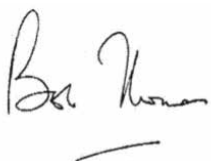
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established 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.



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# 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:** Solar radiation is the major environmental cause of melanoma. People should be encouraged to use a combination of sun protection measures during the sun protection times.

**Risk factors include:**

- a personal history of skin cancer
- a family history of melanoma
- increased numbers of naevi on a total body count (> 100 of more than 2 mm)
- increased numbers of dysplastic naevi
- solarium use
- fair or red hair colour

- poor tanning ability
- tendency to sunburn
- multiple solar keratoses.

**Management of increased risk includes:**

- education about skin self-examination and sun protection advice
- total skin check every six to 12 months
- use of surveillance photography

- sequential dermoscopic imaging
- referral to a dermatologist or cancer geneticist for people with a family history of cancer in two first-degree relatives.

**Early detection:**

Opportunistic identification of high-risk patients with total body cutaneous examination should be practised.

## Step 2

### Presentation, initial investigations and referral

**Signs and symptoms:**

- any changing skin lesions
- a rapidly growing skin lesion
- a change in one or more of the ABCDE criteria (asymmetry, border irregularity, colour variation, large diameter (> 6 mm), evolution)

Note: A minority of cases present as a symmetric nodule (EFG: elevated, firm and growing progressively for more than one month).

**General/primary practitioner investigations:**

A baseline photograph and/or measurement of the lesion should be taken before a period of observation for lesions with a low level of suspicion.

Where melanoma is highly suspected, referral to a dermatologist or surgeon, or excisional biopsy

(by a general practitioner, dermatologist, or surgeon) is appropriate.

**Referral:** The following lesions should be referred to a specialist within two weeks:

- high-risk melanoma (deeply invasive)
- metastatic melanoma
- lesions with histologic uncertainty
- incompletely excised lesions.

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

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

## Step 3

### Diagnosis, staging and treatment planning

**Diagnosis:** The majority of diagnoses occur in the primary care setting.

Specialist management may include complete excision (in rare instances where a partial biopsy was performed pre-referral) or re-excision with recommended margins, and imaging.

**Staging:** Sentinel lymph node biopsy (SLNB) can be offered to assess lymph node metastases. If metastatic melanoma is detected, a complete regional lymphadenectomy (LND) can be performed.

**Treatment planning:** Selected patients with advanced stage melanoma, lymph node involvement or melanoma in unusual sites are best

managed by multidisciplinary teams (MDTs) in a specialist facility.

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

**Communication – lead clinician to:**

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

<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.

### Dermatological assessment:

to assess the risk of further melanomas, surveillance planning and to detect synchronous primaries.

**Surgery** with direct primary closure can be undertaken in a primary care setting for excision biopsy and selected re-excision. Surgery for all other excisions, SLNB and regional LND should be undertaken by a surgeon.

**Radiation treatment** may be of benefit to patients with specific types of primary melanoma or with loco-regional and distant metastatic disease.

**Chemotherapy and immunotherapy** should be considered for all patients with advanced melanoma given their potential for long-term improvement in patient outcome (Olszanski 2014).

**Palliative care:** Early referral 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 risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

For detailed information see [http://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/cp111.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/cp111.pdf).

## Step 5

### Care after initial treatment and recovery

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

**Treatment summary** (provide a copy 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
- contact information for key care providers.

**Follow-up care plan** (provide a copy to the 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 secondary prevention and healthy living
- discuss the follow-up care plan with the general practitioner.

## Step 6

### Managing recurrent, residual and metastatic disease

**Detection:** Patients should be made aware that self-examination is essential for any new or changing skin lesion, cutaneous lump or persistent new symptom.

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

**Palliative care:** Early referral 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/carer
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.



# Summary – optimal timeframes

**Timeframes for diagnosis and referral** – Timeframes should be informed by evidence based guidelines where they exist, whilst recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress. The following recommended timeframes are based on expert advice from the Melanoma Working Group:

Step in pathway	Care point	Timeframe
Presentation, Initial Investigations and Referral	2.1 Signs and symptoms	GP consultation should be within one week of identifying a definitive change (listed in Section 2.1)
	2.2 Initial investigations by the GP	Biopsy should be performed within 2 weeks of the decision it is necessary. The result of the biopsy should be available within one week.
	2.3 Specialist appointment	Referral to a specialist should be within 2 weeks
Diagnosis, Staging and Treatment Planning	3.2 Staging	Staging investigations should be completed within 2 weeks
	3.3 Treatment planning	Where appropriate, multidisciplinary discussion should be conducted before implementing treatment.

# Intent of the optimal cancer care pathway

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidence-based 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 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 2007b).

## 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 (MDT) 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) 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, with a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

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

- malnutrition (as identified using a validated malnutrition screening tool or presenting with weight loss)
- breathlessness
- pain
- difficulty managing fatigue
- difficulty sleeping
- distress, depression or fear
- poor performance status
- 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 organisations should be considered including:

- a psychologist or psychiatrist
- a genetic counsellor
- community-based support services (such as Cancer Council Australia)
- a dietitian
- an exercise physiologist
- an occupational therapist
- a physiotherapist
- peer support groups (contact the Cancer Council on 13 11 20 for more information)
- a social worker
- nurse practitioner and/or specialist nurse
- specialist palliative care
- a speech therapist.

See the **appendix** for more information on supportive care and the specific needs of people with melanoma.

## 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 meetings, supportive care screening and 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 individual 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, 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.

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 providers' and healthcare system's responsibility 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, as well as recordings or written summaries of their consultations. QPL interventions are effective in improving communication and the 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 interventions in treatment of cancer, as well as establishing the role of psychological, supportive care 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 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.

The pathway covers cutaneous melanomas. Ocular and periocular melanomas are not included in this pathway given the differences in the risk factors and management of these tumours.

## Step 1: Prevention and early detection

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

### 1.1 Prevention

Solar radiation is the major environmental cause of melanoma. Sunburning, particularly to the point of skin peeling, and use of solariums should be avoided. A balance is required between avoiding an increased risk of melanoma by excessive sun exposure and achieving enough sun exposure to maintain vitamin D levels.

Protecting children from sunburn and long-term overexposure to the sun reduces their risk of developing skin cancer later in life.

Effective prevention strategies (to be used during sun protection times) include using long-sleeved clothing, broad-brimmed hats, broad-spectrum sunscreens with an SPF of 30 or higher, shade and sunglasses. People should be encouraged to use a combination of sun protection measures during the sun protection times to avoid reliance on one form of sun protection alone as an adjunct to sun avoidance and other sun protective measures.

### 1.2 Risk factors

People with the following are at higher risk of developing a melanoma:

- a personal history of melanoma
- a family history of melanoma
- increased numbers of naevi on a total body count (> 100 of more than 2 mm)
- increased numbers of dysplastic naevi
- solarium use
- fair or red hair colour
- poor tanning ability
- tendency to sunburn
- a history of blistering sunburn
- a previous non-melanoma skin cancer
- multiple solar keratoses.

Management of increased risk should include:

- education from a general practitioner or dermatologist about skin self-examination and sun protection advice for the person at risk and their family.

Management for people at high risk may include:

- a total skin check every six to 12 months by a dermatologist or general practitioner with skills in dermoscopy
- surveillance photography for people with multiple naevi
- sequential dermoscopic imaging.

Mutation testing for estimating melanoma risk remains a research tool. Melanoma risk is assessed using the clinically determined risk factors listed above. Referral to a specialist (either dermatologist or cancer geneticist) for people with a family history of cancer in two first-degree relatives may be helpful.

## **1.3 Early detection**

### **1.3.1 Screening**

In the absence of any substantial evidence as to its effectiveness in reducing mortality, general population-based screening cannot be recommended (CCA and ACN 2008b).

Opportunistic identification of high-risk patients with subsequent total body cutaneous examination on these patients should be practised (CCA and ACN 2008a). It is important for practising clinicians to be aware of high-risk groups in the population and that those in such groups also be aware of their status and establish a surveillance program (CCA and ACN 2008b); regular total skin examination should be practised.



## 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 following should be assessed by a primary care practitioner:

- any changing skin lesions, including new lesions or lesions that do not respond to treatment (note that lesions do not have to be pigmented)
- a rapidly growing skin lesion that remains unresolved after one month
- a change in one or more of the specific features of ABCDE criteria (asymmetry, border irregularity, colour variation, large diameter (> 6 mm), evolution) (CCA and ACN 2008a). These begin as with an in situ phase, which is flat and changing in size, shape and colour for months to a year or more before elevation due to invasion develops.

Note: A significant minority of cases present as a symmetric nodule that is frequently non-pigmented at that grows progressively for more than one month (EFG: elevated, firm and growing progressively for more than one month) (Kelly et al. 2003). These are invasive from the outset and grow more quickly over weeks to months with elevation, deeper invasion and earlier onset of bleeding and ulceration.

#### Timeframe for general practitioner consultation

Within one week of identifying a definite change (listed above).

## 2.2 Assessments by the general or primary medical practitioner

General practitioners play a pivotal role in the early detection and management of melanoma.

A period of observation is appropriate for lesions with a low level of doctor suspicion for non-invasive melanoma. The general practitioner should educate the patient about what to report between appointments. The time interval between reviews should be judged by reference to the rapidity of evolution (one to six months). A baseline photograph and/or measurement of the lesion should be taken before a period of observation.

Dermatoscopy is useful in enhancing diagnosis. In implementing dermatoscopy it is imperative that appropriate training and skill maintenance be observed (CCA and ACN 2008a).

Where melanoma is strongly suspected, or repeated consultations about a specific lesion occur, referral to a specialist (dermatologist or surgeon) or excisional biopsy (performed by a general practitioner, dermatologist or surgeon) is appropriate.

Complete excision of the lesion is the best approach as this samples the entire lesion, provides maximum tissue for histological diagnosis and allows the architecture of the tumour to be studied. If the lesion is very large, in a cosmetically sensitive location or where excisional biopsy will cause loss of function, biopsy techniques such as punch, shave and incisional biopsy may be appropriate (CCA and ACN 2008a). Where partial biopsy is used, the practitioner needs to be aware of the limitations of each type of biopsy. Partial biopsy is particularly prone to error in histological diagnosis (Ng et al. 2010) and punch biopsy diagnosis indicating a benign melanocytic lesion should not be relied upon.

It is imperative that all biopsy material be submitted for histopathological examination by a pathologist.

For detailed information on recommended biopsy methods and indications refer to the Cancer Council Australia and Australian Cancer Network's *Clinical practice guidelines for the management of melanoma in Australia and New Zealand* at <[http://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/cp111.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/cp111.pdf)>.

### Timeframe for completing investigations

Timeframes for undertaking a biopsy and receiving results 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 Melanoma Working Group:<sup>1</sup>

- Biopsy should be performed within two weeks of the decision that it is necessary.
- The result of the biopsy should be available within one week.

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

## 2.3 Referral

The following lesions should be referred to a specialist with expertise in melanoma:

- high-risk melanoma (deeply invasive)
- metastatic melanoma
- lesions with histological uncertainty
- incompletely excised lesions where surgical expertise is required for appropriate margins.

Further referral may be required from:

- the dermatologist to a surgeon
- the surgeon to a different surgeon
- the surgeon to dermatologist for a total skin check
- the specialist to a multidisciplinary service depending on the prognosis and site of the tumour.

Healthcare providers should provide clear routes of rapid access to specialist evaluation.

Referral 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
- the results of current clinical investigations (biopsy and pathology reports)
- the results of all prior relevant investigations
- notification if an interpreter service is required.

### Timeframe for referral to a specialist

Referral timeframes 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 Melanoma Working Group. Referral to a specialist should be within two weeks.

The supportive and liaison role of the general practitioner 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 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:

- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety and 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 people 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:

- reassure the patient about the timing of referral and treatment, if the lesion has not been removed
- provide the patient with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment if required.

## 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 MDT members should determine the treatment plan.

### 3.1 Diagnostic workup

All patients should have a complete skin check.

Unlike other cancers, the majority of tests to confirm a melanoma diagnosis occur in the primary care setting before specialist referral.

Specialist management may include:

- complete excision (in rare instances where a punch, shave or incisional biopsy was performed pre-referral) or re-excision with recommended margins
- imaging (in some circumstances).

Reporting of biopsy results should be in the synoptic format as described in the National Health and Medical Research Council melanoma guidelines at <[http://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/cp111.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/cp111.pdf)>.

### 3.2 Staging

Staging is the cornerstone of treatment planning following surgical excision.

Initial staging of melanoma occurs with the complete excision of the primary lesion. The majority (thickness of < 0.75 mm with adequate margins) do not require further investigation.

Sentinel lymph node biopsy (SLNB) can be offered to patients as prognostic information and to assess the presence of lymph node metastasis. If metastatic melanoma is detected, a complete regional lymphadenectomy (LND) may be performed in a second procedure after SLNB (NCI 2014).

Node-negative primary melanoma does not require imaging staging investigations.

If a patient has palpable lymph nodes or evidence to suggest metastatic disease, then specialist referral for further investigations will be required.

#### Timeframe for completing staging

Timeframes for completing staging 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 following recommended timeframes are based on the expert opinion of the Melanoma Working Group. Staging investigations should be completed within two weeks.

### 3.3 Treatment planning

Selected patients with advanced stage primary melanoma, lymph node involvement and melanoma in unusual sites (for example, mucosal and disseminated melanoma) are best managed by MDTs in a specialist or melanoma facility (CCA and ACN 2008b).

#### 3.3.1 Responsibilities of the multidisciplinary team

The responsibilities of the MDT 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 relevant team members, including the patient's 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 and their 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 melanoma

The MDT 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 2007b).

Team members may include a:

- care coordinator (as determined by MDT members)\*
- dermatologist\*
- medical oncologist\*
- nuclear medicine physician\*
- nurse (with appropriate expertise)\*
- pathologist\*
- radiation oncologist\*
- radiologist/imaging specialists\*
- surgeon\*
- clinical trials coordinator
- dietitian
- general practitioner
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- psychiatrist
- psychologist
- social worker.

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

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

Where appropriate, multidisciplinary discussion should be conducted before implementing treatment.

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

## 3.4 Research and clinical trials

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

With emerging therapies, it has become particularly important that opportunities to access to potentially useful clinical trials are explored.

- 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, 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 the common issues outlined in the **appendix**, specific needs that may arise at this time include:

- help with psychological and emotional distress while adjusting to the diagnosis, treatment phobias, existential concerns, stress, difficulties making treatment decisions, anxiety and depression, 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 people from culturally and linguistically diverse backgrounds.

### 3.5.3 Communication with the patient

The lead clinician should:

- establish if the patient has a regular or preferred general practitioner
- 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 meeting
- offer individualised melanoma information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, and community and national cancer services and support groups
- use a professionally trained interpreter to communicate with people from culturally and linguistically diverse backgrounds
- 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 meetings and notify the general practitioner if the patient does not attend appointments
- 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 meetings (consider using video or teleconferencing).

## Step 4: Treatment

Step 4 outlines the treatment options for melanoma. For detailed information on treatment options refer to the Cancer Council Australia and Australian Cancer Network's *Clinical practice guidelines for the management of melanoma in Australia and New Zealand* at <[http://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/cp111.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/cp111.pdf)>.

### 4.1 Treatment intent

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

- curative
- loco-regional control
- 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 appropriate, advance care planning should be initiated with patients at this stage. Advance care planning can have 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 Dermatological assessment

Dermatological assessment should be considered as a preliminary treatment option for assessing the risk of further melanomas, surveillance planning and for detecting synchronous primaries.

#### 4.2.2 Surgery

The definitive treatment of a primary melanoma involves an adequate margin of skin and subcutaneous fat. For a melanoma in situ this is 5 mm. For an invasive melanoma the margins of 10 mm or 20 mm will be considered depending on its thickness and specific type of melanoma (as per National Health and Medical Research Council guidelines).

#### Surgery in a primary care setting

Surgery under local anaesthetic with direct primary closure can be undertaken by a dermatologist or a general practitioner with adequate training and experience. This can take place in the primary care setting for excision biopsy and selected re-excision for melanomas.

#### Surgery by the specialist team

Surgery for all other excisions, SLNB and regional LND should be undertaken by a surgeon with adequate training and experience.

There is a role for resection of regional and distant metastatic melanoma in selected cases.

### **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 with institutional credentialling and agreed scope of practice in melanoma (ACSQHC 2004).

#### **4.2.3 Radiation treatment**

Radiotherapy may be of benefit to patients:

- with specific types of primary melanoma (for example, desmoplastic melanoma with neurotropic spread and lentigo maligna when the patient is unsuitable for surgery)
- with loco-regional and distant metastatic disease.

### **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 with institutional credentialling and agreed scope of practice in melanoma (ACSQHC 2004).

Radiation oncology centre characteristics for providing safe and quality care include:

- access to allied health
- access to CT scanning for simulation and planning
- trained radiotherapy nurses, physicists and therapists.

#### **4.2.4 Chemotherapy or drug therapy**

All patients with advanced melanoma should be considered for systemic treatment following recent advances in therapeutic options responding to previously unmet medical needs and given their potential for long-term improvement (Olszanski 2014).

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

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

- Medical oncologists (FRACP 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.

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 for delivering treatment safely (including dealing with extravasation of drugs)
- appropriate molecular pathology access
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

#### **4.2.5 Targeted therapies – immunotherapy**

Efforts should be made to identify those patients who may benefit from targeted therapies (immunotherapy).

A range of biological and targeted therapies are increasingly being used to treat patients with melanoma. Recent advances in therapeutic options have shown long-term improvement in patient outcome (Olszanski 2014).

### **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; Zimmermann et al. 2014). 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).

#### **Further information**

- Refer patients and carers to Palliative Care Australia at <[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.

With emerging therapies, it has become particularly important that opportunities to access to potentially useful clinical trials are explored.

- For more information visit <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.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 MDT to discuss safety and efficacy and 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 the 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 MDT 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 available 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, assessment and referral to appropriate health professionals and/or organisations 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:

- decline in mobility and/or functional status as a result of treatment
- emotional and psychological issues including, but not limited to, body image concerns, fatigue, 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
- physical symptoms such as pain and fatigue, loss of appetite or weight loss
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic), which may require referral to a specialist psychologist, psychiatrist or social worker
- possible wound infections following grafts, which may require review by a wound specialist
- upper and lower limb lymphedema, which may require referral to a trained lymphoedema practitioner
- 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)
- 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:

- 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 possible side effects of treatment, self-management strategies and emergency contacts
- provide tailored accurate information about appearance-altering treatment such as scarring and/or disfigurement that occurs with skin grafting
- 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 MDT.

## 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 their 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 MDT. 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 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 followup, 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 managing 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 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

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence and 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.

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

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

Surveillance after curative treatment for melanoma is as follows:

- Tumours less than 1 mm thick: follow-up for two years unless the patient is at high risk for a second primary melanoma due to high naevus numbers, multiple dysplastic naevi or a history of melanoma in close relatives. Patients should be seen four- to six-monthly for two years and then less frequently, according to risk factors, for an indefinite period.
- Tumours more than 1 mm thick: follow-up three- to four-monthly for the first two years, six-monthly review to five years, and lifelong yearly review thereafter.
- Stage III disease: follow-up three- to four-monthly for the first two years, six-monthly for the next two to three years, and then as deemed clinically necessary.
- For follow-up to manage metastatic disease: Depending on clinical circumstances, patients should be seen one- to four-monthly for an indefinite period.

Follow-up assessment should include a comprehensive history and full examination including examination of the primary site and lymph nodes and potential sites of metastases.

Patients should be made aware that self-examination is essential.

After the removal of a primary melanoma, in most circumstances follow-up care can safely and effectively be provided in the primary care setting. For patients who have had treatment for metastatic melanoma, the short-term follow-up should be shared between the specialist and the primary care practitioners until specialist assessment is no longer considered necessary.

Access to a range of health professions may be required including physiotherapy, occupational therapy, nursing, 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.

With emerging therapies, it has become particularly important that opportunities to access to potentially useful clinical trials are explored.

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



## 5.4 Support and communication

### 5.4.1 Supportive care

Screening using a validated screening tool, assessment and referral to appropriate health professionals and community-based support services is required to meet the needs of individual patients, their family and carers.

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

- treatment for physical symptoms such as pain and fatigue, loss of appetite or weight loss
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic) may require referral to a specialist psychologist, psychiatrist or social worker
- possible wound infections following grafts, which may require review by a wound specialist
- upper and lower limb lymphedema, which may require referral to a trained lymphoedema practitioner
- 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 people 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 managing cancer-related fatigue, cognitive changes, 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; Zimmermann et al. 2014). This is particularly true for poor prognosis cancers (Temel et al. 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 the 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 at <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

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

The lead clinician should:

- 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 patient's general practitioner regarding:

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the patient's progress
- recommendations from the MDT
- 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, residual local or metastatic disease.

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

Patients should be advised to be alert for any new or changing skin lesion, cutaneous lump or persistent new symptom. This should be a trigger for further medical assessment.

### 6.2 Multidisciplinary team

Where relevant, there should be timely referral to the original MDT (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 disease, performance status, previous management and patient preferences.

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.

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

### 6.4 Palliative care

Evidence suggests that early referral to palliative care is associated with better outcomes in terms of quality of life, survival and aggressiveness of care at the end of life (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014).

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 preferred place of death.

#### Further information

- Refer patients and carers to Palliative Care Australia at <[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.

With emerging therapies, it has become particularly important that opportunities to access to potentially useful clinical trials are explored.

- 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 the common issues outlined in the **appendix**, specific issues that may arise include:

- 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 (including advance care planning, appointing a power of attorney and completing a will)
- Treatment for physical symptoms such as pain and fatigue, loss of appetite or weight loss
- 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
- the need for appropriate information for people from culturally and linguistically diverse backgrounds
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic), which may require referral to a specialist psychologist, psychiatrist or social worker
- possible wound infections following grafts, which may require review by a wound specialist
- upper and lower limb lymphedema, which may require referral to a trained lymphoedema practitioner.

### **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, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

### **6.6.3 Reduced functional capacity**

Reduced functional capacity/reduced capacity to work or operate machinery (including driving) may occur at this stage.

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

The lead clinician should ensure there is adequate discussion with the patient and carer about the diagnosis 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 their 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 or 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 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 general practitioner and palliative care team are essential in the management of the patient. The team may consider seeking additional expertise from a:

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

There might also be a recommendation for accessing:

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

Consideration of the appropriate place of care and the patient's 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 at <[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.

With emerging therapies, it has become particularly important that opportunities to access to potentially useful clinical trials are explored.

- 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 the common issues identified in the **appendix**, specific issues that may arise at this time include:

- symptoms including pain, fatigue, nausea, vomiting, anorexia, breathlessness and confusion
- 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 people with advanced disease such as accessing superannuation early, 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
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic), which may require referral to a specialist psychologist, psychiatrist or social worker
- possible wound infections following grafts, which may require review by a wound specialist
- upper and lower limb lymphoedema, which may require referral to a trained lymphoedema practitioner.

### 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.

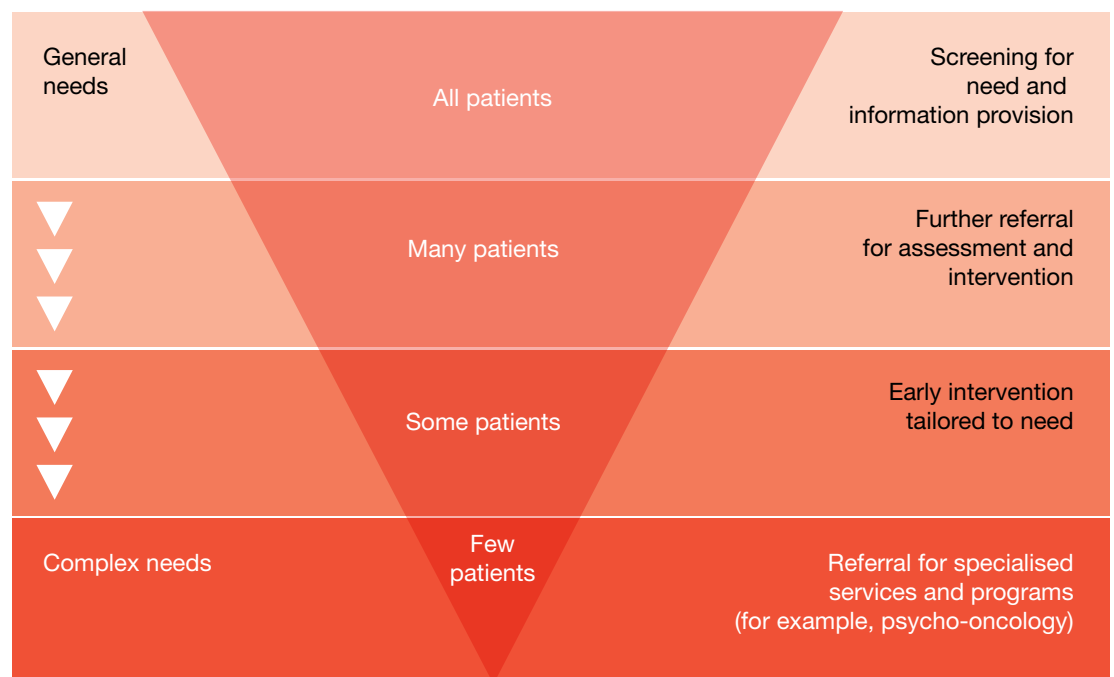
# Appendix: Supportive care

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 melanoma who may require referral to appropriate health professionals and/or organisations include the following:

### **Physical needs**

- Disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic) may require referral to a specialist psychologist, psychiatrist or social worker.
- Possible wound infections following grafts may require review by a wound specialist.
- Upper and lower limb lymphoedema may occur and referral to a trained lymphoedema practitioner may be needed.
- Cachexia/anorexia can occur as a result of disease or treatment. Validated malnutrition screening tools should be used at the key points in the care pathway to identify patients at risk of cachexia/anorexia and refer to a dietician for nutrition intervention.
- Alteration of cognitive functioning in patients treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information.
- Referral to a pharmacist may be useful for people 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 people may have disabling symptoms and may benefit from referral to psychology services.
- Distress can occur, particularly for patients with deeply indented scars, such as those that occur with skin grafting and/or with disfigurement, particularly of the face, head and neck. Providing patients with tailored and accurate information prior to treatment, facilitating patient decision making about appearance-altering treatment, and meeting others with similar personal experience may assist some people. Support and counselling from a specialist psychologist, psychiatrist or social worker may also be required.
- 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 and 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 melanoma 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 or 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.

## Social/practical needs

- A diagnosis of melanoma can have significant financial, social and practical impacts on patients, carers and families as outlined above. The additional costs of prosthetic, camouflage or lymphoedema services and wound/skin dressings may have a significant financial impact. A referral to a social worker should be considered for further assessment and identification of financial and practical support available.
- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.

## 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 (aged over 70 years)

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 (COSA) 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.

## Adolescents and young adults

Recent years have seen the emergence of adolescent and young adult (AYA) oncology as a distinct field due to lack of progress in survival and quality-of-life outcomes (Ferrari et al. 2010; NCI & USDHHS 2006; Smith et al. 2013). The significant developmental change that occurs during this life stage complicates a diagnosis of cancer during the AYA years, often leading to unique physical, social and emotional impacts (often as a result of disfigurement and scarring from appearance-altering treatment) for young people at the time of diagnosis and throughout the cancer journey (Smith et al. 2012).

In caring for young people with cancer, careful attention to the promotion of normal development is required (COSA 2011). This requires personalised assessments and management involving a multidisciplinary, disease-specific, developmentally targeted approach informed by:

- understanding the developmental stages of adolescence and supporting normal adolescent health and development alongside cancer management
- understanding and supporting the rights of young people
- communication skills and information delivery that are appropriate to the young person
- addressing the needs of all involved, including the young person, their family and/or carer(s)
- working with educational institutions and workplaces
- addressing survivorship and palliative care needs.
- An oncology team caring for a young person with cancer must:
  - ensure access to expert AYA health professionals who possess knowledge specific to the biomedical and psychosocial needs of the population
  - understand the biology and current management of the disease in the AYA age group
  - consider clinical trials accessibility and recruitment for each patient
  - engage in proactive discussion about fertility preservation and the late effects of treatment and consider the patient's psychosocial needs
  - provide treatment in an AYA-friendly environment.

## Culturally and linguistically diverse communities

For people from culturally and linguistically diverse 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.

## 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 survival 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 2013). 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 2013):

- 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.

# Resources

## For patients, families and carers

### 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, practical advice on how to care, and finding services

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

### Melanoma Patients Australia

A national network of support and information to patients, their families and carers

- Telephone: 1300 88 44 50
- <[www.melanomapatients.org.au](http://www.melanomapatients.org.au)>

### Skin & Cancer Foundation Australia

Information about melanoma and patient support

- <[www.skincancer.asn.au](http://www.skincancer.asn.au)>

## For health professionals

### Australasian Lymphology Association

Professional organisation promoting best practice in lymphedema management, research and education

- Telephone: (03) 9895 4486
- <[www.lymphoedema.org.au](http://www.lymphoedema.org.au)>

### 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)>

### Australia and New Zealand Melanoma Trials Group (ANZMTG)

Promotes and supports melanoma trials for investigators and consumers

- Telephone: (02) 9911 7352
- <[www.anzmtg.org](http://www.anzmtg.org)>

### Cancer Australia

Information for health professionals including guidelines, cancer guides, 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 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, 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 performed in 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 (for example, specialist physician, surgeon, oncologist, 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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Cancer Australia  
Cancer Council Victoria Strategy and Support  
Consumer representatives  
Department of Health & Human Services, Cancer Strategy and Development  
Grampians Integrated Cancer Service  
Monash University  
North Eastern Melbourne Integrated Cancer Service  
Peter MacCallum Cancer Centre  
Royal Hobart Hospital  
Western Health

## Medical colleges and peak organisations

Allied Health Professions Australia  
Australia and New Zealand Melanoma Trials Group  
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  
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