

Optimal care pathway for people with head and neck cancers



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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 healthcare providers and covers a range of institutions, both public and private. The optimal cancer care pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

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

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

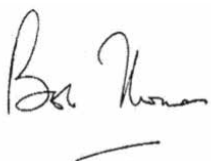
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established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

The NCERG has subsequently endorsed these new optimal cancer care pathways, which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

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

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

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



Professor Robert Thomas OAM
Chief Advisor Cancer, Department of Health & Human Services

Summary

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

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

Step 1

Prevention and early detection

Prevention: The uptake of human papillomavirus (HPV) vaccination by Australian boys and girls 12–13 years of age should be encouraged. Strategies to curb alcohol intake and smoking and reduce to ultraviolet (UV) exposure will reduce future head and neck cancer burden.

Risk factors: Users of both tobacco and alcohol have a 50-fold (or greater) increased risk of developing head and neck cancer. Other risk factors include:

- age (over 40 years)
- sex (male)
- pre-existing oral lesions
- HPV exposure
- Epstein-Barr virus infection (for nasopharyngeal cancer)
- immunosuppressed patients
- ionising radiation exposure
- UV skin exposure (for skin cancer)
- inherited conditions.

Step 2

Presentation, initial investigations and referral

Signs and symptoms: The following symptoms should be investigated if they persist for more than three weeks, especially if there is more than one symptom:

- hoarseness or altered speech
- difficulty swallowing
- persistent sore throat (particularly with earache)
- unexplained neck or parotid lump
- mouth ulcer or mass
- leukoplakia (white or red patches) of oral mucosa
- unexplained tooth mobility and/or non-healing dental extraction site
- spitting or coughing up blood
- unilateral blockage of the nose or ear.

General/primary practitioner investigations:

Ultrasound-guided fine needle aspiration cytology

(USgFNAC) of a node if there is suspicion of malignancy. Non-fine-needle aspiration (FNA) biopsies should not be carried out in a non-specialist setting.

Referral: All patients with a suspected head and neck cancer should be referred to a head and neck specialist with expertise in these cancers and who is affiliated with a multidisciplinary team within two weeks of identification by a general practitioner or dentist.

Communication – lead clinician to:¹

- offer smokers advice about smoking cessation
- 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 and staging: The following investigations should be undertaken:

- complete head and neck examination, including endoscopy
- scans to evaluate the primary site, preferably prior to biopsy to avoid the effect of upstaging from the oedema
- FNA for assessment of patients with neck or thyroid lumps inaccessible to biopsy
- biopsy (arranged by a specialist).

Staging:

- Computerised tomography (CT) and magnetic resonance imaging (MRI) of both the primary site and neck lymph nodes.
- MRI is for assessing tumours of the nasopharynx and paranasal sinuses and for cancers with skull base invasion, soft tissue intracranial extension and perineural tumour spread.

- Positron emission tomography (PET) CT is an important staging tool in locally advanced head and neck cancers.

Treatment planning: All newly diagnosed patients should be discussed in a multidisciplinary team meeting so that a treatment plan can be recommended.

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

Communication – lead clinician to:

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

¹ Lead clinician – the clinician who is responsible for managing patient care.

The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

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.

Having access to specialist nursing and allied health disciplines (in particular specialist speech pathology and dietetics) is important for managing the physical, psychological and social/practical needs that may arise with head and neck cancer treatment.

Treatment options:

Surgery: This is a treatment option for the majority of head and neck cancer patients.

Radiation therapy: This can be delivered as primary treatment for organ conservation, usually concurrently with chemotherapy. It is also given following surgery (postoperatively) for patients at high risk of locoregional recurrence.

Chemotherapy or drug therapy:

Concurrent or adjuvant chemoradiation has now become the standard of care in locally advanced head and neck squamous cell carcinoma. There are selected clinical scenarios where neoadjuvant chemotherapy (prior to radiation therapy) is also appropriate.

Palliative care: Early referral can improve quality of life. Referral should be based on need, not prognosis.

Communication – lead clinician to:

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

For detailed information see <<http://oralcancerfoundation.org/treatment/pdf/head-and-neck.pdf>>.

Step 5

Care after initial treatment and recovery

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 patient's general practitioner.

Step 6

Managing recurrent, residual and metastatic disease

Detection: Most cases of recurrent head and neck cancers are identified through routine follow-up or when the patient presents with symptoms.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, performance status, 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

Optimal timeframes: 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 expert advice from the Head and Neck Cancers Working Group.

Step in pathway	Care point	Timeframe
Presentation, initial investigations and referral	2.2 Initial investigations by general practitioner	Symptoms should be investigated if they persist for more than three weeks.
	2.3 Specialist appointment	Within two weeks of initial referral.
Diagnosis, staging and treatment planning	3.3 Multidisciplinary team meeting	Within two weeks of specialist appointment.
Treatment	4.2 Treatment (surgery, chemotherapy)	Within four weeks of decision to treat.
	4.2 Treatment (adjuvant radiation)	Overall treatment time from surgery to commencement of adjuvant radiation therapy should be not more than six weeks.
	4.2 Treatment (radiation)	If radiation therapy is the primary treatment modality the time from decision to treat to starting treatment should be within four weeks for curative intent and within two weeks for palliative intent.

Intent of the optimal cancer care pathway

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

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

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

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

Patient-centred care

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

Safe and quality care

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

Multidisciplinary care

This is an integrated team approach to healthcare in which medical 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 have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

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

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

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

Common indicators in patients with these cancers 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 or linguistically diverse background.

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

- a clinical 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 pathologist.

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

Care coordination

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

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

Improving care coordination is the responsibility of all health professionals involved in the care of 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 2007c).

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 provider's 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 and recordings or written summaries of their consultations. QPL interventions are effective in improving communication, psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

Research and clinical trials

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

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

Optimal cancer care pathway

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

The pathway covers the following head and neck cancers: mouth or oral cancer; salivary gland cancer; pharyngeal or throat cancer, incorporating nasopharyngeal, oropharyngeal and hypopharyngeal cancers; laryngeal cancer; and nasal or paranasal sinus cancer. The pathway is also applicable to thyroid cancer, cancers of the cervical oesophagus, cancers of unknown primary that first appear in the head and neck, and cancer in the skin of the head and neck in the context of high risk and advanced skin cancer.

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

Step 1: Prevention and early detection

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

1.1 Prevention

All current smokers should be offered smoking cessation advice and support to quit. Head and neck clinicians are encouraged to support the uptake of human papillomavirus (HPV) vaccination by Australian boys and girls 12– 13 years of age.

Strategies to curb alcohol intake and smoking and to reduce ultraviolet (UV) exposure will also reduce future head and neck cancer burden.

1.2 Risk factors

Users of both tobacco and alcohol have a 50-fold (or greater) increased risk of developing head and neck cancer (Maier et al. 1992; Rodriguez et al. 2004). Cigarette smoking is considered the most important risk factor for head and neck cancer (Saman 2012). Betel nut and tobacco chewers are at higher risk for oral cancers.

Other risk factors include:

- age (over 40 years)
- sex (male)
- pre-existing oral lesions
- HPV exposure (Curado & Hashibe 2009; Marur & Forastiere 2008)
- Epstein-Barr virus infection (for nasopharyngeal cancer)
- immunosuppressed patients
- ionising radiation exposure
- UV skin exposure (for skin cancer)
- inherited conditions including Fanconi's anaemia, ataxia-telangiectasia syndrome, Bloom's syndrome and Li-Fraumeni cancer syndrome.

1.3 Early detection

1.3.1 Screening

There are no formal screening programs for head and neck cancers. Opportunistic screening should be an integral part of care provided by medical and dental practitioners during routine patient attendance.

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 symptoms should be investigated if they persist for more than three weeks, especially if there is more than one symptom:

- hoarseness
- difficulty swallowing
- persistent sore throat (particularly together with earache)
- unexplained neck or parotid lump
- mouth ulcer or mass
- leukoplakia (white or red patches) of oral mucosa
- unexplained tooth mobility and/or non-healing dental extraction site
- altered speech
- spitting or coughing up blood (coughing up blood from the chest requires a respiratory physician referral)
- unilateral blockage of the nose or ear.

Most of these problems have non-malignant causes but require further assessment. The presence of multiple signs and symptoms, particularly in combination with other underlying risk factors, can indicate an increased risk of head and neck cancer.

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

Investigations prior to referral:

- If there is suspicion of malignancy or a neck lump persists or grows (including thyroid, salivary gland or lymph node), ultrasound-guided fine-needle aspiration cytology (USgFNAC) of a node.
- Non-fine-needle aspiration (FNA) biopsies should not be carried out in a non-specialist setting (SA Health 2013).

2.3 Referral

All patients with a suspected head and neck cancer should be referred to a head and neck specialist with expertise in these cancers who is affiliated with a multidisciplinary team.

Referral should be to an ear, nose and throat (ENT)/head and neck surgeon for investigation of suspected larynx or pharynx cancer, or to an ENT/head and neck surgeon or oral and maxillofacial surgeon for investigation of suspected oral cancer.

The symptoms listed in 2.1 warrant prompt referral to a specialist, highlighting the concern that there may be a cancer.

Referral for suspected head and neck cancers should incorporate appropriate documentation sent with the patient including:

- a letter that includes important psychosocial history and relevant past history, family history, current medications and allergies
- results of current clinical investigations (imaging and pathology reports)
- results of all prior relevant investigations
- any prior imaging, particularly a hard copy or CD of previous chest x-rays and computed tomography (CT) scans where online access is not available (lack of a hard copy should not delay referral)
- notification if an interpreter service is required.

Timeframe for referral to a specialist

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

According to expert advice from the Head and Neck Cancers Working Group, the first specialist appointment should take place within two weeks of the initial referral from the general or primary practitioner.

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:

- treatment for physical and psychological symptoms as appropriate
- information about and assistance with smoking and alcohol cessation (required if the patient is a smoker/drinks alcohol)
- 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:

- offer advice about smoking cessation including nicotine replacement therapy and/or other therapies if the patient is a smoker
- 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.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer, and for planning subsequent treatment.

The guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.

3.1 Diagnostic workup

The following investigations should be undertaken under the guidance of a specialist:

- complete head and neck examination by an experienced clinician, including endoscopy
- scans to evaluate the primary site, preferably be performed prior to biopsy of the primary site to avoid the effect of upstaging from the oedema caused by biopsy trauma (Roland & Paleri 2011)
- FNA for the diagnostic assessment of patients with neck or thyroid lumps inaccessible to biopsy
- biopsy (arranged by specialist) to confirm pathological diagnosis (via endoscopy or under anaesthetic if required).

3.2 Staging

Staging is the cornerstone of treatment planning. CT and magnetic resonance imaging (MRI) of both the primary site and neck lymph nodes, are the preferred imaging modality in the preoperative work-up of patients with head and neck cancer.

MRI is the preferred imaging modality for assessing tumours of the nasopharynx and paranasal sinuses, and for cancers with skull base invasion, soft tissue intracranial extension and perineural tumour spread (Royal College of Radiologists 2006).

Positron emission tomography (PET) CT is an important staging tool in locally advanced head and neck cancers, particularly for defining the nodal classification, distant metastatic disease and detection of synchronous primaries (Connell et al. 2007; Lonneux et al. 2010).

3.3 Treatment planning

Treatment planning should be done at a multidisciplinary team meeting.

3.3.1 Responsibilities of the multidisciplinary team

These are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the multidisciplinary team meeting
- evaluate the complexity of the case and whether treatment can safely be delivered locally or whether it should be delivered in collaboration with a larger (linked) head and neck centre
- 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 and coordination and continuity of care as well as providing information and support to the patient and their family.

The special needs dentist should assess and arrange management of the dentition for patients likely to have surgery or radiation to the mouth and jaws.

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 head and neck cancers

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

Team members may include a:

- care coordinator (as determined by multidisciplinary team members)*
- clinical trials coordinator
- dietitian*
- general practitioner
- head and neck surgeon*
- medical oncologist*
- nuclear medicine physician
- nurse (with appropriate expertise)*
- occupational therapist
- oral and maxillofacial surgeon*
- palliative care specialist
- pathologist*
- pharmacist
- physiotherapist
- plastic and reconstructive surgeon*
- psychiatrist
- psycho-oncology
- radiation oncologist*
- radiation therapist
- radiologist/imaging specialists*
- social worker
- special needs dentist*
- speech pathologist.*

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

3.3.4 The optimal timing for multidisciplinary team planning

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

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

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

Timeframe for multidisciplinary team discussion

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.

According to expert advice from the Head and Neck Cancers Working Group, the following timeframes are recommended:

- The time from the specialist appointment to discussion at a multidisciplinary team meeting should be within two weeks.

3.4 Research and clinical trials

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

- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

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).

A detailed rehabilitation plan should be agreed on by the multidisciplinary team before treatment begins. The plan should include dental, facial prosthetics, nutritional, speech, swallowing, psychological and social rehabilitation considerations.

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:

- treatment for physical symptoms
- management of oral side effects of head and neck cancer treatments, which may require the involvement of a special needs dentist during the planning, treatment and follow-up of patients
- pre-treatment screening for nutritional status, oral health and communication and swallowing function followed by (if appropriate)
 - a prompt referral to the required discipline if problems are identified (for example, dietetics, speech pathology)
 - enteral nutrition for high-risk patients, with relevant referrals made (for example, gastro-intestinal surgery, dietetics)
- guidance for financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members)
- support for alcohol and/or drug addiction
- information about and assistance with smoking cessation if the patient is a smoker
- 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 that their health information will be available to the team for discussion at the multidisciplinary team meeting
- offer individualised head and neck cancer 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, community and national cancer services and support groups
- use a professionally trained interpreter to communicate with people from culturally or linguistically diverse backgrounds
- if the patient has remedial risk factors such as smoking, betel nut chewing, or alcohol misuse, provide information about cessation.

3.5.4 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the patient's general practitioner regarding the treatment plan and recommendations from multidisciplinary team meetings
- 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 team meetings (consider using video- or teleconferencing).

Step 4: Treatment

Step 4 outlines the treatment options for head and neck cancers. For detailed information on treatment options refer to the *NCCN clinical practice guidelines in oncology: head and neck cancers* (NCCN 2014) at <<http://oralcancerfoundation.org/treatment/pdf/head-and-neck.pdf>>.

Head and neck cancer management is complex due to the multiple sites, stages and histologies.

Establishing teams with sufficient caseload to build expertise and experience in the management of these cancers can improve patient survival.

4.1 Treatment intent

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

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure, or
- 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 their family/carer prior to beginning treatment.

If appropriate, advance care planning should be initiated with patients at this stage as there can be 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 Surgery

Surgery is a treatment option for the majority of head and neck cancer patients.

The training and experience and treatment centre characteristics

Surgeons must have FRACS qualifications or equivalent, and have adequate training and experience in head and neck surgery, with institutional credentials and agreed scope of practice within this area.

All surgeons performing head and neck cancer resections will have completed a head and neck surgical fellowship or equivalent. It is also necessary for the surgeon to have ongoing and regular attendance and a commitment to multidisciplinary meetings, and continuing professional development in head and neck oncology. All cancer surgeons should actively participate in regular audits of their surgical results, and their oncological outcomes.

There is evidence to suggest that surgeons who undertake a high volume of resections have better clinical outcomes for complex cancer surgery (Cheung et al. 2009).

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

- an intensive care unit
- appropriate nursing and theatre resources to manage complex head and neck surgery
- 24-hour medical staff availability
- ward staff with specific training in looking after patients who have undergone tracheostomy, laryngectomy or gastrostomy
- specialist dietetics support
- 24-hour operating room access
- pathology
- in-house access to interventional radiology
- ability to perform or refer for ancillary study.

There is evidence to suggest that centres with higher caseloads have better clinical outcomes (Cheung et al. 2009; Peters et al. 2010). Optimally, patients should be treated at centres managing more than 100 new mucosal head and neck cancer patients per year (particularly complex cases). Centres that do not have such a caseload should routinely refer such cases to a centre with greater experience.

4.2.2 Radiation therapy

Radiation therapy is a treatment option for the majority of head and neck cancer patients.

It can be delivered for curative intent as primary treatment for organ conservation, usually concurrently with chemotherapy. It is also given following surgery (postoperatively) for patients at high risk of locoregional recurrence. For a subset of patients it is given in combination with chemotherapy. Interrupting and prolonging a course of radical radiation therapy should be avoided.

Patients should have access to a dietitian and a speech pathologist within the radiation therapy centre, who should liaise closely with their counterparts in the patient's local support team.

Training, experience and treatment centre characteristics

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

- radiation oncologist (Fellowship of the Royal Australian and New Zealand College of Radiologists or equivalent) with adequate training and experience with institutional credentialling and agreed scope of practice in head and neck cancers (ACSQHC 2004); it is expected that he/she will have completed a 12-month fellowship in head and neck radiation oncology
- affiliated with or regular attendance at the multidisciplinary team meetings.

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

- close collaboration with head and neck subspecialty medical oncologists
- access to allied health, especially dietetics and speech pathology
- access to CT scanning for simulation and planning
- access to MRI and PET fusion for radiation therapy planning
- trained radiation therapy nurses, physicists and radiotherapists.

4.2.3 Chemotherapy or drug therapy

Chemotherapy alone, unlike either surgery or radiation therapy, cannot cure head and neck cancer, but concurrent or adjuvant chemoradiation has now become the standard of care in locally advanced head and neck squamous cell carcinoma because it has been shown to improve local control and add a survival benefit compared with radiation therapy alone (Roland & Paleri 2011). There are selected clinical scenarios where neoadjuvant chemotherapy (prior to radiation therapy) is also appropriate.

Chemotherapy is also used in palliation.

Training, experience and treatment centre characteristics

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

- Medical oncologists (Fellowship of the Royal Australasian College of Physicians 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 to deliver 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.

Timeframe for commencing/completing treatment

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

According to expert advice from the Head and Neck Cancers Working Group, the following timeframes are recommended:

- The time from the multidisciplinary team meeting decision to treat to initial treatment should be within four weeks.
- Overall treatment time from surgery to commencement of adjuvant radiation therapy should be no more than six weeks.
- If radiation therapy is the primary treatment modality the time from decision to treat to starting treatment should be within four weeks for curative intent and within two weeks for palliative intent.

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. This is particularly true for poor-prognosis cancers (Temel et al. 2010).

Evidence suggests that referral to palliative care at the time of diagnosis of metastatic head and neck cancers is associated with better outcomes in terms of quality of life, survival and less aggressive treatment at the end of life (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 via <www.palliativecare.org.au>.

4.4 Research and clinical trials

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

For more information visit <www.australiancancertrials.gov.au>.

4.5 Complementary or alternative therapies

The lead clinician should discuss the patient's use (or intended use) of complementary or alternative therapies not prescribed by the multidisciplinary team to identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base.

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

Some complementary therapies may assist in some cases and the treating team should be open to discussing 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 multidisciplinary team who have knowledge of complementary and alternative therapies (such as a clinical pharmacist, dietitian or psychologist) to help them reach an informed decision.

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

Further information

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

4.6 Support and communication

4.6.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), 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 the following.

Physical needs include:

- treatment for physical symptoms such as pain and fatigue
- management of oral side effects of head and neck cancer treatments, which may require the involvement of a special needs dentist during the planning, treatment and follow-up of patients
- dietitian input for malnutrition, which is common during treatment and the acute recovery phase (the benefits of enteral nutrition should also be considered and home enteral nutrition should be available if required)
- referral to a speech pathologist for patients who present with symptoms of aspiration (coughing when eating or drinking) or hoarseness, or people who have undergone a laryngectomy communication and swallowing difficulties prior to or during head and neck cancer treatment
- decline in mobility and/or functional status as a result of treatment
- assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications (referral to a pharmacist may be required).

Psychological needs include:

- assistance with cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties
- disfigurement and scarring from appearance-altering treatment, which may require referral to a specialist psychologist, psychiatrist or social worker
- supports with emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns
- a referral to a speech pathologist to manage and maximise any communication impairments, an occupational therapist or psychologist for social skills training and/or a social worker for family liaison to help to reduce psychosocial difficulties (difficulty with communication and social interactions is relatively common for patients with head and neck cancer and can place the patient at high risk of depression).

Social/practical needs include:

- referral to the appropriate discipline (for example, social work, speech pathology or dietetics) for support with the additional costs related to managing ongoing impairments such as communication devices, enteral feeding and chronic wound management
- guidance about financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members)
- a need for increased community supports as patients recover from treatment.

Information needs include:

- availability of written or verbal (taped) information of the planned treatment and its side effects
- information about and assistance with smoking/alcohol cessation if relevant
- advice on how to maintain good oral hygiene during and after radiation therapy
- appropriate information for people from culturally and linguistically diverse backgrounds.

4.6.2 Communication with the patient, carer and family

The lead clinician should ensure referral for:

- intensive dietary advice during treatment to prevent weight loss, increase intake and reduce interruption to radiation therapy
- discussing the treatment plan with the patient and carer, including the intent of treatment and expected outcomes (provide a written plan)
- providing the patient and carer with information on possible side effects of treatment, self-management strategies and emergency contacts
- initiating a discussion regarding advance care planning with the patient and carer.

4.6.3 Communication with the general practitioner

The lead clinician should:

- discuss with the general practitioner their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding
 - the treatment plan, including intent and potential side effects
 - supportive and palliative care requirements
 - the patient's prognosis and their understanding of this
 - enrolment in research and/or clinical trials
 - changes in treatment or medications
 - recommendations from the multidisciplinary team.

Step 5: Care after initial treatment and recovery

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

5.1 Survivorship

In the past two decades, the number of people surviving head and neck cancer has increased; patients receiving treatment for head and neck cancer have a high survival rate relative to other cancers. 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 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 management of symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient's needs are met.

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

5.2 Post-treatment care planning

5.2.1 Treatment summary

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

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

5.2.2 Follow-up care

The patient will remain under specialist supervision until their acute toxicities have resolved. Referral to a pharmacist may be useful for people managing multiple medications.

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines.

Responsibility for follow-up care should be agreed between the lead clinician, the patient's general practitioner, relevant members of the multidisciplinary team 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.

It should be acknowledged that there is a poor evidence base for optimal follow-up schedules; it is an area worthy of further research.

Treatment should be individualised.

Current practice is:

- Patients are usually followed up to a minimum of five years, with a prolonged follow-up for selected patients.

Patients should be followed up at least three-monthly in the first two years and four- to six-monthly in the subsequent years:

- three-monthly until two years post-treatment
- four-monthly until three years post-treatment
- six-monthly until five years post-treatment.

Thyroid-stimulating hormone values should be checked every six to 12 months in patients whose treatment involved their thyroid – that is, the thyroid was included in a radiation field or surgical resection, or the pituitary fossa (nasopharyngeal cancer). Patients with abnormal results should be referred to an endocrinologist for opinion and treatment.

Access to a range of health professions may be required including physiotherapy, occupational therapy, nursing, social work, dietetics, speech pathology, clinical psychology and palliative care.

5.3 Research and clinical trials

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

For more information visit <www.australiancancertrials.gov.au>.

5.4 Support and communication

5.4.1 Supportive care

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

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

Physical needs

- Patients should be treated for physical symptoms.
- Management of oral side effects of head and neck cancer treatments may require the involvement of a special needs dentist during the planning, treatment and follow-up of patients.
- Patients may experience a decline in mobility and/or functional status as a result of treatment.
- Lymphoedema may occur and referral to a trained lymphoedema practitioner may be needed.
- Continued speech pathology input is important for the assessing and managing communication and swallowing problems that may occur following head and neck cancer treatment; these include patients who present with symptoms of aspiration (coughing when eating or drinking) or hoarseness.
- Patients with dysphagia should be referred for an appropriate instrumental swallow assessment as required, to help guide the management of their swallowing difficulties and minimise aspiration risk.
- Continued speech pathology input is also required for people who have undergone a laryngectomy to maximise communication, humidification/airway management and swallowing outcomes. A referral to a physiotherapist with expertise in the respiratory management of these patients may also be of benefit.
- Patients requiring oral nutrition support or fed via gastrostomy or a nasogastric tube should receive support from dietitians with expertise in managing these interventions before, during and after treatment.
- Malnutrition can occur as a result of disease or treatment. Validated malnutrition screening tools such as the malnutrition screening tool (MST) should be used at the key points in the care pathway to identify patients at risk of malnutrition and refer to a dietitian for nutrition intervention.
- General rehabilitation needs to be considered in patients who have poor physical capacity.

Psychological needs

- Cognitive changes as a result of treatment (such as altered memory, attention and concentration) should be monitored.
- Emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns may need attention.
- Disfigurement and scarring from appearance-altering treatment may require referral to a specialist psychologist, psychiatrist or social worker.
- Difficulty with communication and social interactions is relatively common for patients with head and neck cancer and can place the patient at high risk of depression. A referral to a speech pathologist to manage and maximise any communication impairments, an occupational therapist or psychologist for social skills training and/or a social worker for family liaison may help to reduce psychosocial difficulties.

Social/practical needs

- The additional costs related to managing ongoing impairments, such as communication devices, enteral feeding and chronic wound management, may require referral to the appropriate discipline (for example, social work, speech pathology or dietetics) for further assessment and identification of appropriate funding support.
- Guidance about financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members) may be required.
- There may be a need for increased community supports as patients recover from treatment.

Information needs

- If the patient has remedial risk factors such as smoking, betel nut chewing or alcohol misuse, provide information about cessation.
- Provide 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.

Physiotherapy should be available to all patients undergoing major head and neck treatment.

5.4.3 Palliative care

Evidence suggests that 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 (Bakitas et al. 2015; Haines 2011; Temel et al. 2010).

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 via <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 multidisciplinary team
- any shared care arrangements
- a process for rapid re-entry to medical services for patients with suspected recurrence or treatment side effects.

Step 6: Managing recurrent, residual or metastatic disease

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

6.1 Signs and symptoms of recurrent, residual or metastatic disease

Most cases of recurrent head and neck cancers are identified through routine follow-up or when the patient presents with symptoms.

6.2 Multidisciplinary team

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

6.3 Treatment

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

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 (Bakitas et al. 2015; Haines 2011; Temel et al. 2010).

Where appropriate, 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 via <www.palliativecare.org.au>.

6.5 Research and clinical trials

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

For more information visit <www.australiancancertrials.gov.au>.

6.6 Support and communication

6.6.1 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 issues that may arise include the following.

Physical needs

- Patients should be treated for physical symptoms.
- Patients may experience a decline in mobility and/or functional status as a result of treatment.
- Swallowing and communication difficulties may occur in the presence of residual, recurrent or metastatic disease, and may require referral to a speech pathologist. It is important to consider the patient's overall prognosis and quality of life in the management of these (for example, the benefit of oral feeding irrespective of aspiration risk).
- Continued speech pathology input is also required for people who have undergone a laryngectomy to maximise communication, humidification/airway management and swallowing outcomes. A referral to a physiotherapist with expertise in the respiratory management of these patients may also be of benefit (for example, for advice regarding daily sputum production, coughing and forced expectoration).
- Validated malnutrition screening tools such as the malnutrition screening tool (MST) should be used at diagnosis or treatment planning to identify patients at risk of malnutrition and refer to a dietitian for nutrition intervention.
- Enteral nutrition may be considered in certain patients with residual, recurrent or metastatic disease, though consideration of the patients overall prognosis and quality of life should be considered.

Psychological needs

- Help with the emotional distress of dealing with a potential recurrence, anxiety/depression, interpersonal problems, stress and adjustment difficulties may be required.
- Disfigurement and scarring from appearance-altering treatment may require referral to a specialist psychologist, psychiatrist or social worker.
- Cognitive changes as a result of treatment (such as altered memory, attention and concentration) may need attention.
- Difficulty with social interactions can place the patient at higher risk of depression, which is relatively common for patients with head and neck cancer. A referral to a speech pathologist to manage and maximise any communication impairments and an occupational therapist or psychologist for social skills training may help to reduce psychosocial difficulties.

Social/practical needs

- The additional costs related to managing ongoing impairments, such as communication devices,
- enteral feeding and chronic wound management, may require referral to the appropriate discipline (such as social work, speech pathology or dietetics) for further assessment and identification of appropriate funding support.
- Support with legal issues (including advance care planning, appointing a power of attorney and completing a will) may be required.
- Guidance for financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members) may be needed.

Information needs

- If the patient has remedial risk factors such as smoking, betel nut chewing or alcohol misuse, provide information about cessation.
- Provide appropriate information for people from culturally and linguistically diverse backgrounds.

6.6.2 Rehabilitation

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

6.6.3 Communication with the patient, carer and family

The lead clinician should ensure there is adequate discussion with the patient and carer about the 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 functional status is declining. Step 7 is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach the end of life, as well as the needs of their family and carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the patient and their family.

7.1 Multidisciplinary palliative care

If not already underway, 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 palliative care team may consider seeking additional expertise from a:

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

The team might also recommend accessing:

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

Consideration of an appropriate place of care and preferred place of death is essential.

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

Further information

Refer patients and carers to Palliative Care Australia via <www.palliativecare.org.au>.

7.2 Research and clinical trials

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

For more information visit <www.australiancancertrials.gov.au>.

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 the following.

Physical needs include:

- treatment for physical symptoms
- support for upper airway obstruction (if required)
- support from dietitians with expertise in feeding via gastrostomy or a nasogastric tube (if required)
- support for a decline in mobility and/or functional status.

Psychological needs include:

- specific needs that may benefit from the involvement of a pastoral care worker, psychologist or social worker.

Social/practical needs include:

- information for patients and families about arranging a funeral
- bereavement support for family and friends
- legal issues relevant to people with advanced disease such as accessing superannuation early, advance care planning, powers of attorney and completing a will
- guidance for financial issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members)
- a need for increased community supports.
- Information needs include:
 - education and emergency planning for patients at risk of upper airway obstruction, for both patients and their carers
 - education and emergency planning for patients and carers if carotid blowout syndrome is thought to be likely
 - information regarding a power of medical attorney.

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 transitioning 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.

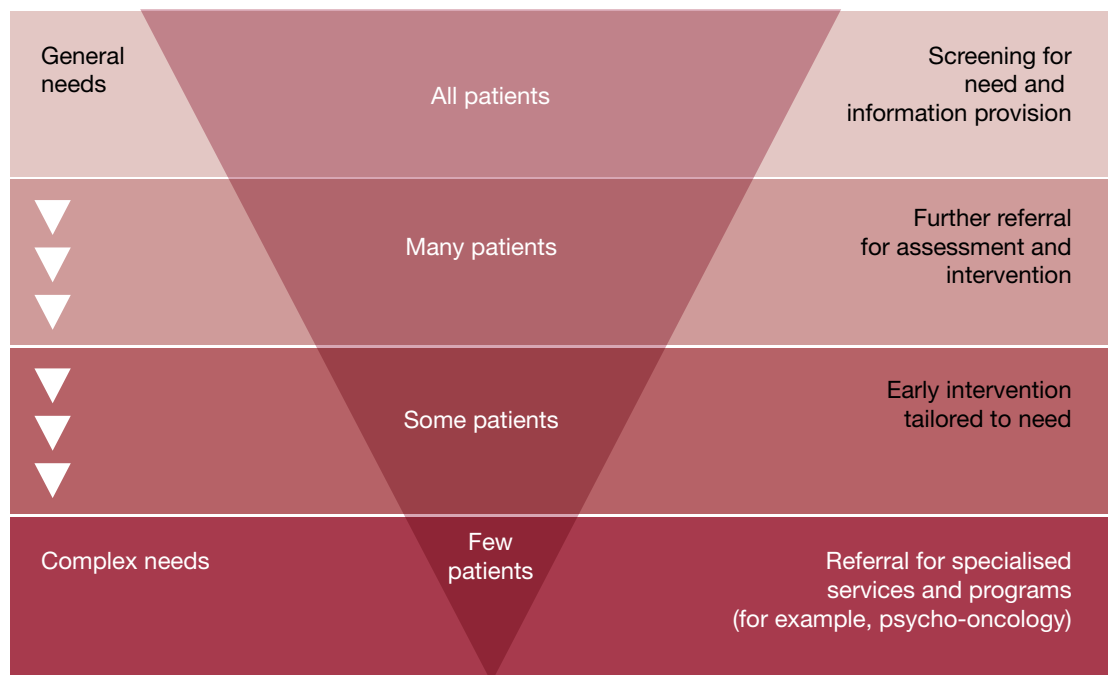
Appendix: Supportive care

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 2004a)
- 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 2004b).

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 head and neck cancer who may require referral to appropriate health professionals and/or organisations include the following.

Physical needs

- Patients should receive treatment for physical symptoms.
- Malnutrition is common prior to diagnosis and during treatment and requires dietitian input. The benefits of enteral nutrition should also be considered at all stages of treatment and recovery.
- Lymphoedema may occur and referral to a trained lymphoedema practitioner may be needed.
- Patients feeding via gastrostomy or a nasogastric tube should receive support from dietitians with expertise in managing these interventions before, during and after treatment.
- Patients who present with communication and swallowing impairments before, during and after treatment should be referred to a speech pathologist. This includes patients who present with symptoms of aspiration (coughing when eating or drinking) or hoarseness, or people who have undergone a laryngectomy.
- Patients with dysphagia should be referred for an appropriate instrumental swallow assessment by their speech pathologist (for example, a videofluoroscopy or fiberoptic endoscopic evaluation of swallow) as required to help guide the management of their residual swallow function and minimise aspiration risk.
- People who have undergone a laryngectomy should be referred to a speech pathologist to maximise communication, humidification/airway management and swallowing outcomes. A referral to a physiotherapist with expertise in the respiratory management of these patients may also be of benefit (for example, for advice regarding daily sputum production, coughing and forced expectoration).
- Decline in mobility and/or functional status as a result of treatment should be monitored.
- Patients who are planned to be treated with radiation therapy should have a dental assessment and preventive care plan instituted immediately after the decision to treat.
- General rehabilitation needs to be considered in patients who have poor physical capacity.
- Malnutrition can occur as a result of disease or treatment and so should be monitored.
- 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 psycho-social complexities. Access to expert health professionals with knowledge specific to the psychosocial needs of these groups may be required.
- Disfigurement and scarring from appearance-altering treatment may require referral to a specialist psychologist, psychiatrist or social worker.
- 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 a psychology service.
- 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 cancer is having on their life and the disruption to their life plans
 - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
 - experiencing changes in sexual intimacy, libido and function
 - struggling with the diagnosis of metastatic or advanced disease
 - having difficulties with quitting smoking or other drug and alcohol use
 - having difficulties transitioning to palliative care.
- Cognitive changes as a result of treatment (such as altered memory, attention and concentration) may require assessment.
- Help with the emotional distress of dealing with a cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties may be required.
- Emotional distress arising from changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns may require treatment.
- Difficulty with social interactions can place the patient at higher risk of depression, which is relatively common for patients with head and neck cancer. A referral to a speech pathologist to manage and maximise any communication impairments, and an occupational therapist or psychologist for social skills training, may help to reduce psychosocial difficulties.

Fertility preservation

- Consider the need for sperm storage or egg banking before treatment. Referral to fertility counselling may be appropriate.

Social/practical needs

- A diagnosis of these cancers can have significant financial, social and practical impacts on patients, carers and families, as outlined above. 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.
- The additional costs related to managing ongoing impairments, such as communication devices, enteral feeding and chronic wound management, may require referral to the appropriate discipline (such as social work, speech pathology or dietetics) for further assessment and identification of appropriate funding support.
- Legal issues (including advance care planning, appointing a power of attorney and completing a will) may require advice.
- Guidance for financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members) may be required.
- There may be a need for increased community supports as patients recover from treatment.

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.
- If the patient has remedial risk factors such as smoking, betel nut chewing or alcohol misuse, provide information about cessation.
- Provide appropriate information for people from culturally and linguistically diverse backgrounds.

Populations with special needs

Older people with cancer (aged over 70 years)

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

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

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

Paediatrics

The rarity and complexity of child cancer provides a real challenge in delivering optimal care. Despite overall survival rates of more than 80 per cent (NICE 2005), treatment modalities for paediatric cancer are often prolonged and complicated and have a narrow therapeutic index. Side effects of systemic therapy for treating cancer can be more severe for children, including acute organ toxicities, prolonged immunodeficiency and infection.

As a result of these complexities, high-quality evidence-based care is required not only to deliver therapy and supportive care but is essential in the diagnosis phase, post-treatment surveillance and long-term follow-up care. Children with cancer should be managed by specialised paediatric services under a 'shared care' model to ensure a critical mass. These specialised services work with others to enable the provision of supportive care closer to home when it is safe to do so. Children's cancer services actively participate in clinical trials as a way of participating in research and improving outcomes for children.

Evidence shows that best outcomes demand a well-coordinated, timely, multidisciplinary approach requiring effective collaboration of health services working together as a team (Children's Oncology Group 2012; Corrigan & Fieg 2004). Integrated care is fundamental to paediatric cancer care and service delivery.

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 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 with 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 and management of fertility preservation, the late effects of treatment and psychosocial needs
- provide treatment in an AYA-friendly environment.

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.

Culturally and linguistically diverse communities

For people from 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 (Department of Health 2009).

Resource list

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
- <<http://122.102.106.143/cancersurvivorship/Home>>

beyondblue

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

- Telephone: 1300 22 4636
- <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>

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>

Care Search: Palliative Care Knowledge Network

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

- Telephone: (08) 7221 8233
- <www.caresearch.com.au>

For health professionals

Australian Cancer Trials

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

- <www.australiancancertrials.gov.au>

Cancer Australia

Information for health professionals including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets

- <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>

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>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- <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 that is appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

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

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

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

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

Optimal cancer care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

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

Patient management frameworks – 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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Monash University
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Medical colleges and peak organisations invited to provide feedback

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Australian Association of Nuclear Medicine Specialists
Australian and New Zealand Society of Palliative Care
Australia and New Zealand Head and Neck Cancer Society
Australian Chapter of Palliative Medicine, Royal Australasian College of Physicians
Australian College of Nursing
Australian Institute of Radiography
Australian Medical Association
Australian Psychological Society
Medical Oncology Group of Australia

Royal Australasian College of Dental Surgeons
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