



Government of Western Australia
Department of Health
WA Cancer and Palliative Care Network

Head and Neck Cancer Model of Care

2011–2012

© Department of Health, State of Western Australia (2011).

Copyright to this material produced by the Western Australian Department of Health belongs to the State of Western Australia, under the provisions of the Copyright Act 1968 (C'wth Australia). Apart from any fair dealing for personal, academic, research or non-commercial use, no part may be reproduced without written permission of the Health Networks Branch, Western Australian Department of Health. The Department of Health is under no obligation to grant this permission. Please acknowledge the WA Department of Health when reproducing or quoting material from this source.

Suggested citation

Department of Health, Western Australia. Head and Neck Cancer Model of Care.
Perth: Health Networks Branch, Department of Health, Western Australia; 2011.

Important disclaimer:

All information and content in this Material is provided in good faith by the WA Department of Health, and is based on sources believed to be reliable and accurate at the time of development. The State of Western Australia, the WA Department of Health and their respective officers, employees and agents, do not accept legal liability or responsibility for the Material, or any consequences arising from its use.

Table of Contents

Introduction	1
1. Prevention and screening	3
1.1 Prevention	3
1.2 Screening	3
1.3 Surveillance for high risk subjects	4
2. Initial presentation	5
2.1 Recognition of symptoms and signs	5
2.2 Initial medical consultation	5
2.3 Initiation of investigation	5
2.4 Referral guidelines ⁸	6
3. Diagnosis and referral	7
3.1 Type of specialist	7
3.2 Timeframe to see a specialist	7
3.3 Diagnostic investigation	8
3.3.1 Biopsy	8
3.3.2 Computed Tomography (CT)	8
3.3.3 Positron Emission Tomography (PET)	9
3.3.4 Magnetic Resonance Imaging (MRI)	9
3.3.3 Pathology	9
3.4 Conveying a diagnosis of malignancy	9
4. Multidisciplinary team assessment and management planning	10
4.1 The Multidisciplinary Team (MDT)	10
4.2 The Multidisciplinary Meeting (MDM)	11
4.3 MDT treatment care plan	11
5. Treatment	12
5.1 Surgery	12
5.1.1 Training and experience of surgeons	12
5.1.2 Institutional facilities	12
5.1.3 Psychological aspects of surgery	12
5.2 Radiation treatment	13
5.2.1 Appropriate patients for radiotherapy	13
5.2.2 Treating radiation oncologist	13
5.2.3 Institution facilities	13
5.3 Drug therapy	14
5.3.1 Appropriate patients for drug therapy	14
5.3.2 Treating medical oncologist	14
5.3.3 Institution facilities	14

6. Surveillance and follow-up care	15
6.1 Plan for follow-up	15
6.2 Persons involved in follow-up care	15
6.3 Telehealth	16
7. Survivorship	17
7.1 Modulators of relapse risk	17
7.2 Education	17
8. Relapse and retreatment	18
8.1 What should be provided	18
8.2 Management should be discussed by MDT	18
8.3 Nature of treatment	18
8.4 Aspects of supportive care	19
9. Palliative care	19
10. Supportive care	19
10.1 Physical needs	20
10.2 Psychological needs	21
10.3 Practical needs	22
10.4 Information needs	23
Recommendations	24
References	25
Acknowledgements	25

Introduction

Cancer is the leading cause of death in Western Australia, representing 30.6 per cent of all deaths in 2006.¹

Population ageing will significantly increase the number of new cases of cancer over the next ten years, with an estimated 10,000 more cases per annum in Western Australia by 2016.² In 2006, 581 Western Australians were diagnosed with head and neck cancer and there were 113 deaths due to this type of cancer in 2006.³

Cancer is a complex disease to diagnose and treat, and represents a significant burden to patients and their families, the health system, and the community at large. Western Australia's strategic and planned approach to cancer reform includes the establishment of a Ministerial Taskforce for Cancer and implementation of the 'Fighting Cancer' policy and a 'Cancer Services Framework for Western Australia'.

Two significant directions of the Cancer Services Framework are the establishment of integrated cancer services in metropolitan and regional Western Australia, and the development of service delivery and improvement through a tumour streams model.

Since 2004, eight integrated cancer services have been established in metropolitan and regional Western Australia, based on specified geographic populations. The philosophy of an integrated cancer service is that hospitals and primary and community health services develop integrated care and defined referral pathways for the populations they serve. This requires effective collaboration between hospitals and community-based services, including general practitioners. This will promote more effective local coordination of care for cancer patients, and a more rational, evidence-based approach to cancer service planning and delivery.

The Cancer Services Framework also recommended that organ or system-specific tumour streams be adopted to support the delivery and improvement of care. The reasoning behind the tumour streams is that a consistent approach to clinical management based on evidence-based practice will reduce unacceptable variations in care across the state.

Model of care

This document outlines a model of care for the management of head and neck cancer (aero-digestive) in Western Australia. It is designed to be a statement defining best practice care and services within the health care system for a person with head and neck cancer at each stage of the condition. The WA CPCN Model of Care for Cancer 2008 provides the basis for this tumour site-specific model of care.

(http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Cancer_Model_of_Care.pdf)

The ten steps in figure 1 describe the patient-centred journey that provides safe, high quality, evidence-based, and multidisciplinary care thereby resulting in optimum outcomes. Underpinning this journey is the integration of primary care, supportive care, psycho-oncology and palliative care.

Every cancer patient should have appropriate access to specialist cancer care in the formulation and delivery of their care

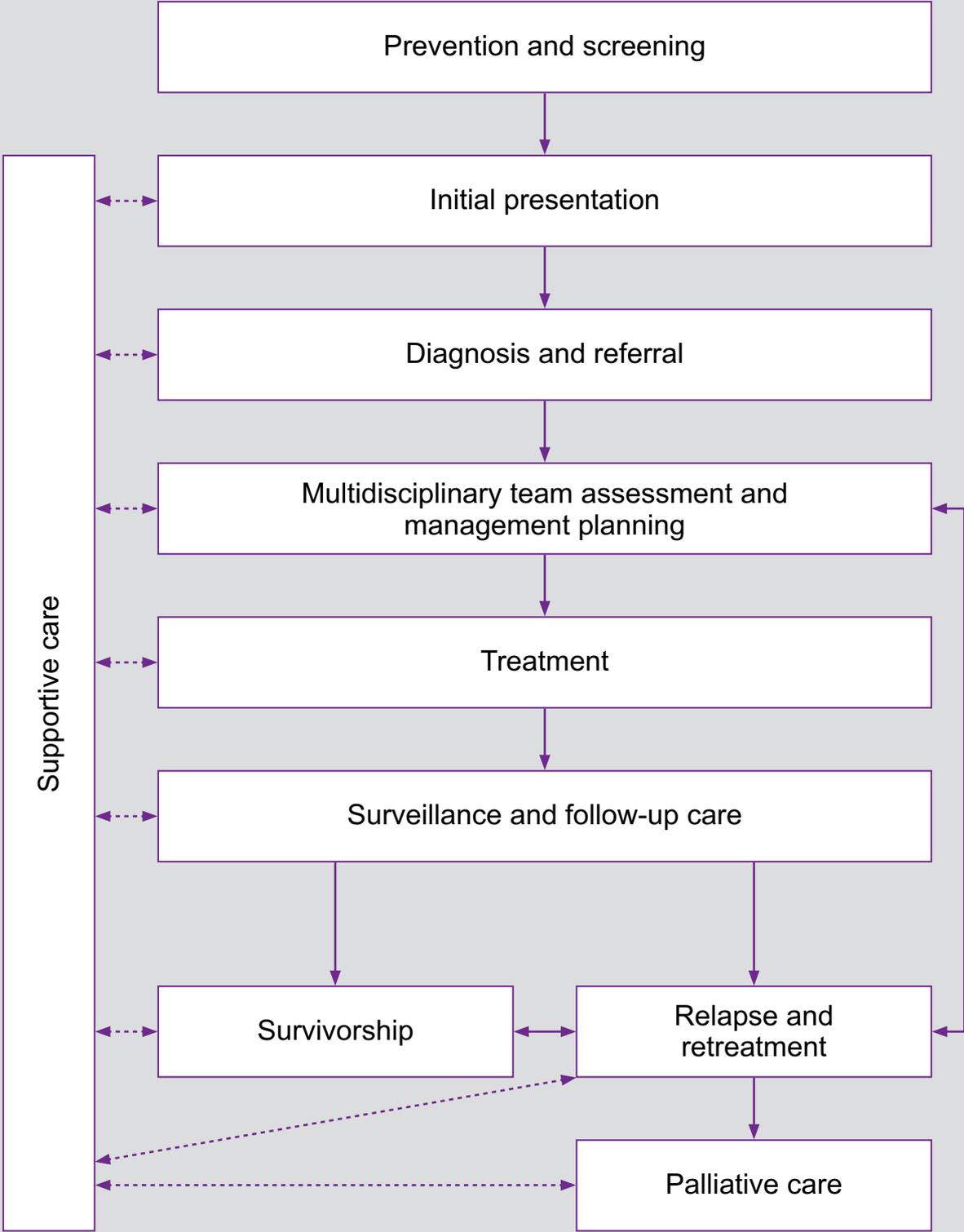


Figure 1. The Patient-centred journey.

1. Prevention and screening

This step discusses the potential of screening in reducing head and neck cancer incidence, the role of prevention strategies, identifies those individuals who may be at higher than average risk of developing head and neck cancer, and outlines symptoms that require further investigation by the general practitioner.

1.1 Prevention

Modifications to a number of lifestyle factors have the potential to reduce head and neck cancer incidence. Reducing smoking is vital, though other lifestyle interventions including alcohol intake, exposure to carcinogens, levels of physical exercise, vegetable consumption, and obesity may also have an impact. The Cancer Council of Australia has produced 'The National Cancer Prevention Policy 2007-2009'⁴ which details the structure and evidence base for previous, existing and future potential interventions.

Interventions of potential benefit include:

- Sustained community educational programs: Anti-smoking campaigns such as 'Make Smoking History' have utilised methods such as mass media advertising and community support-based strategies in order to reduce tobacco-caused harm in the state. Programs such as the 'Go for 2 & 5' campaign in Western Australia have produced measurable changes in behaviour. Public service education programs at a state level should continue with studies of manipulation of content to maximise impact including targeting information on lifestyle modification benefits to specific conditions.
- Education in primary care – The family doctor is a valuable resource with 86 per cent of the population visiting a GP at least annually⁵. Moderate to high-level counselling in this setting has also been shown to bring about behavioural change. Details of risk factors and interventions are presented in 'Guidelines for preventative activities in general practice – The Red Book'⁵ complemented by an outlining of preventative strategies in 'Putting Prevention into Practice – The Green Book'⁶. Primary care-givers should explore ways to incorporate lifestyle education into existing or dedicated consultations supported by the health system through appropriate remuneration.
- School and workplace initiatives: Schools and employers should be encouraged and assisted to provide opportunities for individuals to modify lifestyle habits. Workplace initiatives such as The Cancer Council of Western Australia's 'Fresh Start' Program can help workplaces offer healthy choices to staff by providing supportive quit smoking courses to assist smokers in their quit attempt. School initiatives, including exercise promotion and the availability of healthy food, have a positive impact on the nutritional and exercise habits in a significant proportion of the population.

1.2 Screening

In common with all cancers, head and neck cancer outcomes are significantly superior for earlier stage disease and hence early detection has the potential to reduce mortality. Currently no formal screening programs for any of the head and neck cancers exist in Western Australia.

1.3 Surveillance for high risk subjects

Some individuals are at particularly high risk of head and neck cancer and should be monitored appropriately. Risk factors for cancers of the head and neck include the following⁷:

- tobacco (including smokeless tobacco, sometimes called “chewing tobacco” or “snuff” and passive smoking)
- alcohol
- people who use both tobacco and alcohol are at greater risk for developing these cancers than people who use either tobacco or alcohol alone
- patients with a past history of head and neck cancer are at a higher risk of developing a second aero-digestive tract malignancy (head and neck, lung and oesophagus).

Other risk factors associated with each cancer type include:

- **Oral cavity:** Sun exposure (lip); human papillomavirus (HPV) infection
- **Salivary glands:** Radiation to the head and neck. This exposure can come from diagnostic x-rays or from radiotherapy for noncancerous conditions or cancer
- **Paranasal sinuses and nasal cavity:** Certain industrial exposures, such as wood or nickel dust inhalation
- **Nasopharynx:** Asian, particularly Chinese, ancestry; Epstein Barr virus infection; occupational exposure to wood dust; and consumption of certain preservatives or salted foods
- **Oropharynx:** Poor oral hygiene and HPV infection. The use of mouthwash that has a high alcohol content is a possible, but not proven, risk factor
- **Hypopharynx:** Plummer-Vinson (also called Paterson-Kelly) syndrome
- **Larynx:** Exposure to airborne particles of asbestos.

Note: Tailored interventions are required to reach and educate high-risk groups because they generally constitute socially disadvantaged groups.

2. Initial presentation

Entry into the diagnostic system may come through recognition of symptoms or signs by the patient or their health care professionals.

2.1 Recognition of symptoms and signs

The following symptoms should be investigated if they persist for more than three weeks, especially if there is more than one symptom and if the patient has a history of smoking and/or heavy alcohol consumption:

- hoarse voice
- altered speech
- airway difficulty/stridor
- difficulty swallowing (dysphagia)
- pain on swallowing (odynophagia)
- persistent sore throat (particularly together with earache)
- neck lump
- mouth ulcer or mass
- leukoplakia of oral mucosa
- non-dental mouth or jaw pain (especially with difficulty opening the mouth)
- spitting up blood (coughing up blood from chest requires a respiratory physician referral).

NB: Most of these problems have non-malignant causes, but require further assessment. The symptoms are non-specific, but combinations of symptoms should be investigated.

2.2 Initial medical consultation

- Initial consultation with a general practitioner (GP) should be within two weeks with patient calls being triaged to achieve this and to facilitate more rapid assessment where appropriate.
- GPs, dentists, oral and general surgeons and community pharmacists should have access to educational material on diagnosis and management of head and neck cancer. This might lead to earlier detection/diagnosis and result in simpler treatments with better outcomes.

2.3 Initiation of investigation

GP consultation should include a medical history, psychosocial assessment and physical examination. The symptoms listed in 2.1 warrant prompt referral to a specialist rather than treatments or tests performed by the GP or general dentist.

2.4 Referral guidelines⁸

Urgent referral

Refer urgently patient with:

- an unexplained lump in the neck, of recent onset, or a previously undiagnosed lump that has changed over a period of three to six weeks
- an unexplained persistent sore or painful throat
- unexplained hoarseness for three to four weeks
- unexplained dysphagia (difficulty swallowing), or odynophagia (pain on swallowing) for three to four weeks
- unilateral unexplained pain in the head and neck area for more than four weeks, associated with otalgia (ear ache) but a normal otoscopy
- unexplained ulceration of the oral mucosa or tongue, or mass persisting for more than three weeks
- unexplained red and white patches (including suspected lichen planus) of the oral mucosa, or tongue, that are painful or swollen or bleeding.

*For patients with persistent symptoms or signs related to the oral cavity in whom a definitive diagnosis of a benign lesion cannot be made, refer or follow up until the symptoms and signs disappear. If the symptoms and signs have not disappeared after six weeks, make an urgent referral.

Urgent referral to a dentist

Refer urgently to a dentist, patients with:

- unexplained tooth mobility persisting for more than three weeks:
 - Monitor for oral cancer patients with confirmed oral lichen planus, as part of routine dental examination.
 - Advise all patients, including those with dentures, to have regular dental checkups.

Urgent referral for a chest x-ray

Refer urgently for chest X-ray patients with:

- hoarseness persisting for more than three weeks, particularly smokers aged older than 50 years and heavy drinkers.

*If there is a positive finding, refer urgently to a team specialising in the management of lung cancer. If there is a negative finding, refer urgently to a team specialising in head and neck cancer.

Non-urgent referral

Refer non-urgently patients with:

- unexplained red and white patches of the oral mucosa that are not painful, swollen or bleeding (including suspected lichen planus).

⁸ www.nice.org.uk/nicemedia/pdf/CG027quickrefguide.pdf

3. Diagnosis and referral

This step deals with the investigations that may be required to confirm the diagnosis of cancer and assess the extent (staging) of the disease. This may involve complex tests in different departments/locations and wherever possible should be coordinated to improve patient convenience and wellbeing. Fast tracked, coordinated diagnostic pathways should be implemented at a system level.

The best mechanism of referral is direct communication between the referring doctor and the receiving specialist. It is at this point that any pre-appointment tests (if any) could be arranged. Triage of referrals is then the responsibility of the receiving specialist.

3.1 Type of specialist

- Investigation of suspected head and neck cancer requires referral to an ENT/HN surgeon (FRACS or equivalent).
- Investigation of suspected oral cancer requires referral to an ENT/HN surgeon or an oral maxillo-facial surgeon (FRACS or FRACDS-OMS or equivalent).
- Investigation of a suspected thyroid cancer requires referral to an appropriate specialist (refer Model of Care for Endocrine Tumours (Thyroid)).
- Referral to a surgeon should include clinical information, medical and psychosocial background, radiological films and results, and pathology reports. Information thus far imparted to the patient is also valuable in managing communication. Ideally surgeons should see patients within two weeks of referral, facilitated, where necessary, by direct communication with the surgeon.
- Evidence suggests that specialist surgeons who perform a higher volume of head and neck surgery have superior results in terms of mortality than those carrying out fewer procedures. The characteristics of the surgeon are at least as important as those of the institution.

3.2 Timeframe to see a specialist

For urgent referral, where cancer is strongly suspected, the timeframe to see a specialist should be less than three weeks. The specialist should provide timely communication to the general practitioner about receipt of letters of referral, and the consultation, and should notify the general practitioner if the patient does not attend.

3.3 Diagnostic investigation

Staging is the cornerstone of treatment planning. Pathological staging follows surgical resection. Further staging involves clinical examination and diagnostic imaging including Computed Tomography (CT), Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET) scans and Radionuclide studies where appropriate.

3.3.1 Biopsy

- It is recommended that a biopsy of the primary tumour be obtained, or fine needle aspiration of a neck lump (under ultrasound guidance if necessary), and assessed by a pathologist experienced in head and neck cancer.
- Open biopsy of a neck or parotid lump is contraindicated except in special situations and after assessment in a multidisciplinary team meeting. (For thyroid and salivary gland lumps, definitive pathology may only be possible after histological examination of an excised specimen).
- Ideally, where biopsy is deemed appropriate, results should be available within two weeks of initial GP referral.

Points of relevance include:

- The clinician's patient load and experience in performing FNA cytology and biopsy have been demonstrated to influence performance.
- Clinicians performing these procedures should regularly audit their sampling accuracy for malignant lesions and the rate of inadequate specimens submitted.

3.3.2 Computed Tomography (CT)

CT of the head, neck and chest, is the most useful imaging study to determine the presence of regional and distant metastasis. CT must be available in both the public and private community setting, and in both metropolitan and regional areas. It is appropriate for GPs or specialists to organise a CT scan in a private radiology setting as this will expedite this investigation. Discussion with the specialist at the time of referral may lead to this investigation being performed so that it is available at the time of specialist consultation. Timely access to CT scanning should be available in metropolitan and regional centres.

3.3.3 Positron Emission Tomography (PET)

PET has an increasing role in the diagnostic workup and surveillance of head and neck cancer. Its use may be advantageous in improving the accuracy of staging in locally advanced disease prior to treatment alongside CT/MRI. PET imaging in post treatment surveillance has not yet been fully established.

3.3.4 Magnetic Resonance Imaging (MRI)

The need for this investigation is usually determined by the surgeon and the multidisciplinary team as part of the comprehensive assessment prior to determining the type of treatment.

3.3.5 Pathology

Assessment of tissue specimens by appropriately qualified histopathologists is critical to the diagnostic process. Timely provision (within five working days wherever possible) of these services will usually be carried out by the state pathology service or by private pathology providers.

3.4 Conveying a diagnosis of malignancy

Clearly the initial conveying of a diagnosis of malignancy may cause severe psychological distress. General recommendations for such communications are:

- An arrangement to provide results should be made pre-emptively and in a timely fashion relative to the procedure.
- Where possible conveyance of a malignant diagnosis should be made in person.
- Arrangements should be made for a support person to be present where possible.
- Such report provision should be coordinated by a managing clinician who can also provide contextual information.
- Access to specialist counsellors or psychologists should be provided.
- Written information should be provided.

4. Multidisciplinary team assessment and management planning

This step outlines the members of the Head and Neck Multidisciplinary Team (MDT), essential aspects of Multidisciplinary Meetings and steps required in the development of an MDT treatment care plan.

4.1 The Multidisciplinary Team (MDT)

The multidisciplinary team comprises (in alphabetical order):

- dentist/dental specialist familiar with cancer treatment
- diagnostic radiologist
- dietitian
- ENT/ HN Surgeon
- medical oncologist
- neuro-radiology
- nurse specialist
- palliative care service
- pathologist
- pharmacist
- radiation oncologist
- plastic and reconstructive surgeon
- social worker
- speech pathologist.

With access to:

- pathologist with experience in head and neck cancer
- psycho-oncology services where appropriate (psychologist/psychiatrist)
- other allied health services where appropriate:
 - prosthodontist
 - physical medicine and rehabilitation
 - physiotherapy.
- adjunctive services:
 - neurosurgery
 - ophthalmology
 - nuclear medicine physicians
 - psychiatry
 - addiction services
 - audiology.

**It is essential that the outcomes of the MDT discussion are properly communicated to the general practitioner*

The lead role in the MDT for a case will be determined by the team and must take responsibility for the activity of the team. In most cases the specialist who makes referral to the MDT, will take the lead until responsibility is passed to another practitioner.

4.2 The Multidisciplinary Meeting (MDM)

- MDT meetings should be held weekly at mutually convenient times and locations for participants.
- MDT management in a metropolitan setting should be available to all patients in Western Australia.
- MDT management should be available to all patients no matter where they live. It is expected that patients in rural and remote areas will have access to this care and that this will be co-ordinated by their GP, local specialist or cancer nurse coordinator using video-conferencing or assisted travel where appropriate.
- Ideally, MDT discussion should occur prior to treatment, except in an emergency situation.
- All patients should be further discussed once pathologic staging is known.
- Further investigation and subsequent re-presentation to the MDT may be required.
- The MDM is the ideal forum to identify patients who may be entered into clinical trials.

4.3 MDT treatment care plan

- specifies and documents who will be the primary treating specialist
- fully documents the agreed care plan
- specifies that the agreed care plan should be circulated to all relevant members of the team
- specifies that the progression of care within the MDT should be coordinated ensuring that the patient and all caregivers understand their responsibilities for delivering this care.

Following MDT discussion, the lead clinician is responsible for:

- informing the GP of the planned treatment and their role in this plan
- monitoring the patient's adherence to the agreed treatment plan
- ensuring there is adequate discussion with the patient (and family) of the diagnosis and recommended treatment, including rationale and aim, likely effects, possible outcomes, other treatment options, and psychosocial supports for the patient and family.

5. Treatment

This step is concerned with the type of treatment that will be delivered, who will provide it and where it should be provided to ensure safe, high-quality and effective care.

5.1 Surgery

In certain cancers of the head and neck, surgery will be used as primary management. The institution level of service should be such as to allow surgery in a prompt timeframe relative to diagnosis. Ongoing audit of outcomes should be an intrinsic part of service delivery.

5.1.1 Training and experience of surgeons

Surgical services should be provided by ear, nose and throat, head and neck, plastic and reconstructive surgeons, oral and maxillo-facial surgeons (FRACS, FRACDS-OMS or equivalent) with adequate training and experience in head and neck surgery that enables institutional credentialing and agreed scope of practice within this area.

5.1.2 Institutional facilities

Surgery should be performed in institutions (usually tertiary and secondary hospitals) that provide appropriate facilities including:

- surgeons as specified in 5.1.1
- anaesthetic services
- intensive care/high dependency unit
- nurses with training in tracheostomy care and enteral feeding
- allied health (in particular, dieticians, speech pathologists and physiotherapists)
- access to reconstructive services when appropriate.

5.1.3 Psychological aspects of surgery

Psychological effects from head and neck surgery can be both short and longer term. Providing patients with tailored accurate information prior to treatment, facilitating patient decision making about appearance-altering treatment, and meeting others with similar personal experience may assist some people.

5.2 Radiation treatment

5.2.1 Appropriate patients for radiotherapy

Radiotherapy may be of benefit for:

- definitive treatment of early tumours at certain sites (apart from early squamous cell carcinomas of the mouth and oropharynx)
- post-operative treatment of locally advanced tumours
- concurrent treatment with chemotherapy for definitive treatment of locally advanced tumours as well as for organ preservation as an alternative to surgery e.g. laryngeal tumours
- treatment of loco-regional recurrence
- palliation of symptoms.

Audit of outcomes should form a routine part of service delivery.

Because treatment is limited to tertiary referral centres, infrastructure should be available to provide transport and/or accommodation for patients living a significant distance from treating centres. Details of eligibility for transport funding are available⁸.

5.2.2 Treating radiation oncologist

Radiation treatment should be given by a radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialing and agreed scope of practice within this area.

5.2.3 Institution facilities

Radiation treatment should be performed in accredited institutions with experience in complex treatment planning. This should include the availability of:

- radiation oncologists as specified in 5.2.2
- nurses with training in tracheostomy care and enteral feeding
- radiation oncology medical physicists
- radiation therapists
- dual modality LINACS
- CT planning facilities
- treatment planning system
- access to dentist or dental specialist familiar and experienced in oncology treatments
- allied health (in particular, dieticians and speech pathologists)
- IMRT (Intensity Modulated Radiation Therapy).

NB: Combined therapy with chemotherapy and radiation therapy needs coordination, especially where the facility is not co-located.

5.3 Drug therapy

5.3.1 Appropriate patients for drug therapy

- Chemotherapy may be used in combination with radiotherapy for definitive (curative) treatment.
- Chemotherapy is also used in palliation.

5.3.2 Treating medical oncologist

Drug therapy should be given by a medical oncologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialing and agreed scope of practice within this area.

5.3.3 Institution facilities

Staff requirements to ensure safe delivery of chemotherapy include:

- medical oncologist as described in 5.3.2
- nurses with adequate training in chemotherapy delivery, complications of administration and the handling and disposal of cytotoxic waste
- an appropriately trained pharmacist for chemotherapy/cytotoxic drug preparation and dispensing. The institutional processes enabling preparation and dispensing of cytotoxic drugs should be credentialed to ensure safety and quality
- allied health. In particular, dieticians and speech pathologists require training and experience in head and neck cancer and dieticians require experience in enteral nutrition support, including home enteral nutrition.
- Some components of less complex therapies may be delivered in a setting where no medical oncologist is locally available, by another medical practitioner with training and experience that enables credentialing and agreed scope of practice within this area. 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.

Facilities for safe administration of drug therapy include:

- access to haematology testing
- readily available advice within and after hours
- a clearly defined pathway to emergency care
- ability to care for neutropenic patients
- appropriate pharmacy facilities for preparation of cytotoxics or provision of cytotoxics from such a facility to a secondary institution
- occupational health and safety guidelines are available in relation to handling of cytotoxic drugs, including preparation, waste procedures and spill kits
- guidelines and protocols for the safe administration of drugs including management of extravasation are available and understood.

NB: Combined therapy with chemotherapy and radiation therapy needs effective coordination, especially where the facilities are not co-located.

6. Surveillance and follow-up care

This step concerns the monitoring of the patient following initial treatment. The aim is the early detection of disease relapse. Follow-up care also involves the management of symptoms arising from previous and/or current treatments and from active disease. It also provides reassurance to patients who remain free of disease. A clear documented plan of surveillance should be established and be available to the patient. Multiple visits to multiple specialists should be avoided.

6.1 Plan for follow-up

After treatment patients should be seen*:

- three-monthly until two years post-treatment
- four-monthly until three years post-treatment
- six-monthly until five years post-treatment
- Patients who have received combined modality treatment need coordinated follow-up.
- Current head and neck practice relies on clinical examination rather than investigations in follow-up.
- Patients treated non-surgically may have post-treatment imaging to document response and guide further management.
- Rehabilitation of communication (including speech and voice) and swallowing is of paramount importance.
- Physiotherapy follow-up may include cardiovascular fitness/endurance input; jaw/neck/shoulder/trunk range of movement program; lymphoedema education and treatment, and scar management.
- Adequate oral intake is important and requires follow-up, particularly if ongoing home enteral nutrition support is required.

*Some patients may require more frequent visits depending on clinical status at the discretion of the treating oncologist/surgeon.

6.2 Persons involved in follow-up care

Not all disciplines need to be involved in longer term follow-up. The multidisciplinary team, in consultation with the general practitioner, decides on the lead clinician who will coordinate follow-up. The team is likely to include:

- dietician
- general practitioner, particularly to manage co-morbidities
- speech pathologist as appropriate
- physiotherapist, as appropriate
- treating specialists and supporting care staff, as required.

6.3 Telehealth

Consideration should be given to using telehealth video conferencing facilities for patients in regional and remote locations as this will be of practical use to patients and their families and to their health care team.

In addition to follow-up for general medical care, follow-up may include the following:

- pain and symptom management
- nutritional support
 - enteral feeding
 - oral supplements
- dental care for RT effects
- xerostomia management
- smoking and alcohol cessation
- tracheotomy care
- wound management
- depression assessment and management
- social work and case management
- supportive care
- rehabilitation of communication and swallowing

Responsibility for follow-up investigations needs to be agreed between the designated lead clinician, the general practitioner and the patient, with an agreed plan documented, including notification to the general practitioner or multidisciplinary team member if the patient does not attend. Rural patients have the option of shared follow-up care between the treating specialist and a local or visiting specialist. The general practitioner has a key role in coordination of follow-up.

7. Survivorship

The transition from active to post-treatment care is critical to long term health. Care should be planned and coordinated. Survivors should have knowledge of their increased risk of second/ recurrent cancers or treatment-related morbidities. This encourages them to actively participate in their continuing post-treatment care. This approach is essential so that routine follow-up visits become opportunities to promote a healthy lifestyle, check for cancer recurrence and manage lasting effects of the cancer experience.

Survivorship may be medically-led, particularly through primary care, nurse-led or patient-led. Cancer councils across Australia are developing and evaluating approaches that are patient-centred.

7.1 Modulators of relapse risk

A number of lifestyle factors have been shown to impact on head and neck cancer risk both in the primary (initial diagnosis) and secondary (relapse) settings including:

- smoking – demonstrated as a risk factor in both the primary and secondary settings
- alcohol consumption – demonstrated as a risk factor in both the primary and secondary settings
- poor oral health – demonstrated as a risk factor in both the primary and secondary settings.

7.2 Education

Follow-up provides the opportunity to educate on these factors and encourage beneficial behaviours including:

- ceasing smoking
- reducing or ceasing alcohol consumption
- improving oral health practices
- addressing impaired social function
- psychological distress of treatment, fear of relapse
- provision of survivorship tools.

8. Relapse and retreatment

This step concerns the diagnosis and management of patients who have recurrence of the disease (local or metastatic) and who need assessment regarding further treatment. This assessment may be made by the GP initially with subsequent involvement of the specialist and the MDT. Clinical evaluation and patient discussion will determine the most appropriate treatment which may be curative or palliative in intent. A series of steps should occur at suspected relapse.

8.1 What should be provided

Investigation and diagnosis of potential relapse will usually be made by the specialist coordinating follow-up or by the GP. The following investigations may be indicated for diagnosis and restaging:

- clinical investigation including laryngoscopy if appropriate
- appropriate imaging of sites of persistent or suspicious symptoms
- surgical biopsy of areas of clinical or radiological suspicion
- if relapse is confirmed, diagnostic imaging for the purposes of restaging is appropriate.

8.2 Management should be discussed by MDT

Patients who relapse require expert opinion as to the best plan of management and this should be provided by the MDT. Discussion should be led by the clinician who is responsible for coordinating treatment and follow-up. The management plan should be decided in consultation with the patient and fully documented in the patient record. Participation by the GP and palliative care team may also be appropriate.

8.3 Nature of treatment

Treatment will depend on the location and extent of the recurrence, and on previous management. Treatment may include:

- surgery (for local recurrence)
- radiotherapy (for local recurrence)
- drug therapy +/- radiotherapy.

8.4 Aspects of supportive care

Relapse may impart numerous burdens on the patient:

- the physical burden of disease-related symptoms
- psychological distress
- financial hardship
- extensive time commitments to treatment.

These burdens may be alleviated by consideration of various supportive measures:

- palliative care referral for symptom control
- pain service referral particularly for analgesic procedures
- psychology service referral
- social work consultation to assess potential financial supports
- provision of aspects of care near home where possible.

9. Palliative care

The WA Palliative Care model defines the appropriate approach to symptom management and end of life care.

It is important that patients and their families receive optimal palliative care and early referral for assessment and advice is recommended.

It is also important to recognise that a major component of palliative care involves symptom relief and this may require surgical intervention, radiation therapy or chemotherapy.

(http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Palliative_Care_Model_of_Care.pdf)

10. Supportive care

The supportive care needs of patients with head and neck cancer will vary in severity and complexity along the disease trajectory. Identifying and assessing the supportive care needs of people with head and neck cancer involves a general assessment of the physical, psychological, social, information and spiritual needs. In addition to these general needs, all members of the multidisciplinary team should be aware of the particular needs related to head and neck cancer detailed below which may require intervention from specific members of the multidisciplinary team.

10.1 Physical needs

Potential complication	Action required
<ul style="list-style-type: none"> Persistent communication difficulties, including hoarseness, impaired speech and difficulties voicing, can occur in people who have undergone surgery to the tongue, palate, larynx or who have been treated with radiotherapy 	<ul style="list-style-type: none"> Referral to a speech pathologist
<ul style="list-style-type: none"> Nutritional deficiency and swallowing difficulties 	<ul style="list-style-type: none"> Referral to a dietician Consider oral diet/fluid modification, postural strategies or enteral nutrition Referral to a speech pathologist
<ul style="list-style-type: none"> Treatments have significant impact on long-term oral health Dry mouth, change in taste, difficulty chewing, difficulty with dentures and increased tooth decay are common following treatment, especially radiation therapy 	<ul style="list-style-type: none"> Referral to a dentist specialising in cancer care prior to commencing treatment Referral to a speech pathologist
<ul style="list-style-type: none"> Respiratory symptoms after laryngectomy are both frequent and troublesome. Patients' common complaints include daily sputum production, coughing, forced expectoration and frequent stoma cleaning 	<ul style="list-style-type: none"> Referral to a physiotherapists with expertise in teaching techniques to help relieve these complaints Referral to a speech pathologist Referral to a stoma nurse specialist
<ul style="list-style-type: none"> Loss of libido, change in sexual activity, decreased satisfaction 	<ul style="list-style-type: none"> Sensitive discussion by health care professionals Referral for counselling by clinicians who specialise in this area
<ul style="list-style-type: none"> Severe pain that is difficult to control 	<ul style="list-style-type: none"> Specific pain management techniques coordinated by a medical specialist Other techniques, such as relaxation therapy, distraction and massage, may have short term effects in relieving pain
<ul style="list-style-type: none"> Poor physical capacity 	<ul style="list-style-type: none"> Referral to rehabilitation services
<ul style="list-style-type: none"> Limited neck and shoulder mobility and associated pain. This will impact on activity of daily living such as eating and dressing 	<ul style="list-style-type: none"> Referral to a physiotherapist for musculo-skeletal treatment Referral to an occupational therapist if activities of daily living affected

10.2 Psychological needs

Potential issue	Action required
Anxiety	
<ul style="list-style-type: none"> Stress levels for head and neck patients have been shown to be highest at the point of confirmed diagnosis and recede during the treatment 	<ul style="list-style-type: none"> Referral to a psychologist or psychiatrist as required. Provision of strategies such as information provision, relaxation techniques and meditation Referral to non-government organisation for assistance with psychological issues.
Body image	
<ul style="list-style-type: none"> Many people who have had a laryngectomy experience psychological distress related to body image, particularly related to the stoma Alterations to body image as a result of surgical intervention Alterations in appearance due to side effects of treatment: alopecia, skin changes etc 	<ul style="list-style-type: none"> Providing patients with tailored accurate information prior to treatment, facilitating patient decision-making about appearance-altering treatment, and meeting others with similar personal experience may assist some people. Pre-treatment information session is by an experienced speech pathologist is important in patients facing laryngectomy Support and counselling by a specialist psychologist, psychiatrist or social worker and/or speech pathologist may also be required Meeting others with similar personal experience may assist some people Support and counselling by a specialist psychologist, psychiatrist or social worker may be required Referral to non-government organisation for assistance with psychological issues.

Potential issue	Action required
Sexuality	
<ul style="list-style-type: none"> Changes in physical and sexual functioning, such as loss of libido, change in sexual activity, decreased satisfaction 	<ul style="list-style-type: none"> Requires sensitive discussion and possible referral to a counsellor with expertise in the area
Depression	
<ul style="list-style-type: none"> Difficulty with social interactions can place the patient at higher risk of depression Depression is relatively common for patients with head and neck cancer Psychological distress can be long term, between two and six years after the treatment 	<ul style="list-style-type: none"> Clinicians should regularly screen patients with head and neck cancer for signs of depression Referral to a speech pathologist for communication skills training and an occupational therapist for social skills training may help to reduce psychosocial difficulties. Referral to a psychologist may assist with depression associated with social limitations Several clinicians providing ongoing follow-up care for patients with head and neck cancer should re-assess levels of distress at each follow-up appointment

10.3 Practical needs

Potential issue	Action required
<ul style="list-style-type: none"> Patients face significant financial challenges at various points throughout their cancer journey for several reasons, including loss of income, costs of treatments and costs of travel to treating centres The additional costs related to laryngectomy aids, such as speech aids and voice prostheses The additional costs related to enteral feeding or nutritional supplements 	<ul style="list-style-type: none"> Referral to a social worker for further assessment and identification of appropriate funding support may be required Referral to a non-government organisation Ongoing input and support from speech pathologist for suitable communication aids Patients should have access to equitably priced enteral feeds or nutritional supplements

10.4 Information needs

Potential issue	Action required
Information needs	
<ul style="list-style-type: none"> ■ Many patients who have been given a diagnosis of cancer often have decisions to make regarding their treatment choice. This typically involves complex decision making on side effect profiles and survival benefits with the options presented ■ Patients are given large volumes of information at a time where they are experiencing high levels of anxiety 	<ul style="list-style-type: none"> ■ Patients should be offered written information which is both disease and treatment specific in addition to information on the range of supportive care services which are available to them, such as local support groups. Patients should be given reliable sources whom they can contact for further information should they require it ■ Patients should be offered information in a language they are able to understand. Where English is not the patient's first language, a translator should be available during consultations ■ Clinicians discussing treatment options with patients should offer patients a record of the key points of the discussion including their specific pathology, treatment options and side effect profiles ■ All health professionals should be aware of what information has been given to the patient. Timely communication with the patient's general practitioner is an essential part of this process ■ For smokers: Information about and assistance with smoking cessation is required ■ For people who consume more alcohol than daily recommended limits: Information and support to manage alcohol withdrawal may be required for the patient and the health care professionals caring for the patient ■ Referral to non-government organisation for assistance with information about their cancer and related issues

Recommendations:

1. Evidence-based guidelines/clinical pathways using evidence-based national and international guidelines, for the management of head and neck cancers should be developed and endorsed as the basis for care in WA.
2. Although no formal screening programs for head and neck cancer exist in WA, preventative strategies aimed at reducing the incidence of head and neck cancers may be of benefit.
3. Educational material on diagnosis and management of head and neck cancer should be made available to general practitioners, dentists, oral and general surgeons.
4. Symptoms suggestive of head and neck cancer warrant prompt referral to a specialist rather than treatments or tests performed by the GP or general dentist.
5. Multi-disciplinary team (MDT) management should be available to all patients within WA, no matter where they live.
6. All treatment for cancers of the head and neck should be planned and managed in a multidisciplinary setting in the metropolitan area by a head and neck cancer specialist with access to Multidisciplinary Team Meetings. All members of the treatment MDT should be regarded as having important input.
7. Head and neck cancer MDT meetings should include a dentist/dental specialist.
8. MDT meetings must be appropriately resourced including an MDT coordinator.
9. Head and neck cancer patients require equitable access to treatment and supportive care and adequate provision must be made for the subsidised transport of rural patients and for the accommodation of these patients and their carers close to the Cancer Centre. Consideration should be given by the Health Department to developing the appropriate 'hotel' facilities to allow this to occur.
10. Telehealth facilities should be made available wherever possible, both for initial new patient assessment and post-treatment follow-up where clinically appropriate.
11. The role of the Cancer Nurse Coordinator should be consolidated and recognised as an integral part of the care team.
12. All head and neck cancer patients requiring radiation therapy should have access to the most up-to-date radiotherapeutic techniques.
13. Psychosocial support for all head and neck cancer patients must be included in any treatment program.
14. All head and neck cancer patients should be invited to participate in clinical trials where appropriate.
15. Data collection regarding treatment and outcomes is essential to monitor the quality and safety of care. An appropriate clinical database for head and neck cancer treatment and outcomes should be available and adequately resourced.

References:

1. Australian Bureau of Statistics 3303.0 Causes of Death, Australia, 2006.
2. WA Cancer Registry Cancer Incidence Projections 2007.
3. Cancer Incidence and Mortality in Western Australia, 2006.
A Report of the Western Australia Cancer Registry.
<http://www.health.wa.gov.au/wacr/downloads/rep06a.pdf>
4. The Cancer Council Australia 2007. *National Cancer Prevention Policy 2007-09*.
NSW: The Cancer Council Australia.
5. Harris, M., Bailey, L., Bridges-Webb, C., Furler, J., Joyner, B. et al. 2005.
Guidelines for preventive activities in general practice) – The Red Book (6th edition).
South Melbourne: Royal Australian College of General Practitioners.
6. The Royal Australian College of General Practitioners 'Green Book' Project Advisory
Committee. 2006. *Putting Prevention into Practice: Guidelines for the implementation
of prevention in the general practice setting – The Green Book (2nd edition)*.
South Melbourne: Royal Australian College of General Practitioners.
7. National Cancer Institute. Head and Neck Cancer: Questions and Answers.
www.cancer.gov/cancertopics/factsheet/Sites-Types/head-and-neck.
Accessed 18/12/2008.
8. Quick Reference Guide: Referral Guidelines for Suspected Cancer.
Clinical Guideline 27. June 2005. National Institute for Health and Clinical Excellence.
(www.nice.org.uk/CG027quickrefguide)

Acknowledgements:

The WA Cancer and Palliative Care Network has used, with permission, some of the content and template, used in the '*Victorian Government Cancer Initiatives – Cancer Services Framework Overview*' to produce this Model of Care for Head and Neck Cancer
<http://www.health.vic.gov.au/cancer/framework.htm>

This page has been left blank intentionally.

WA Cancer and Palliative Care Network
Department of Health Western Australia
189 Royal Street, EAST PERTH 6004

Web: www.healthnetworks.health.wa.gov.au/cancer

Email: wacpcn@health.wa.gov.au

Phone: (08) 9222 0202

Fax: (08) 9222 2444

This document can be made available
in alternative formats on request for
a person with a disability.

Produced by WACPCN
© Department of Health 2012