South Australian Head and Neck Cancer Pathway

Optimising outcomes for all South Australians diagnosed with Head and Neck Cancer

September 2013
Development

This clinical cancer pathway was developed by the Head and Neck Cancer Working Group under the auspices of the Statewide Cancer Clinical Network. The project was funded by CanNET SA. CanNET is a Cancer Australia initiative, funded by the Australian Government.

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The Statewide Cancer Clinical Network recommends readers also refer to the Cancer Council Australia Wiki Platform for up to date information and education on clinical practice guidelines.

Statement of intent

This pathway is not intended to be used as a standard of care. Adherence to pathway recommendations will not ensure a successful outcome in every case, nor should they be considered as including all proper methods of care or excluding other acceptable methods of care aimed at the same results.

The ultimate judgement for management must be made by the appropriate health professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This decision should be made only after discussion of the diagnosis and available treatment options with the patient. It is advised, however, that significant departures from the South Australian Head and Neck Cancer Pathway should be documented in the patient’s case notes at the time the relevant decision is made.

Navigating the document

This document contains a number of hyperlinks that you can click to navigate between relevant sections of the pathway and other important resources. Hyperlinks appear as blue and underlined copy. You can also search for keywords throughout the document by selecting CTRL+F and typing in the keyword.
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GPs play an important role in the management of patients at many stages along this patient pathway.

The ‘GP icon’ indicates parts of the pathway of particular relevance to general practitioners.

A factsheet of relevant information for GPs is provided in Appendix F.
ACKNOWLEDGEMENTS

This clinical cancer pathway was developed by the Head and Neck Cancer Working Party of the Statewide Cancer Clinical Network.

Thanks are extended to the clinicians, consumers and non-government organisation contributors to the working party for the personal time and energy afforded to this project.

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EXECUTIVE SUMMARY

BACKGROUND

Head and neck cancer contributes to approximately 2% of all cancer cases and 1.5% of all cancer deaths in South Australia.

Patients with head and neck cancer can require specific clinical and supportive care due to the effect of the tumour and its treatment on swallowing, speech, social interactions and work capabilities.

Management of head and neck cancer requires complex multimodality therapy and surgical expertise from a variety of disciplines. Optimal management is achieved through coordinated service provision between health professionals at private and public hospitals, general practitioners (GPs), Dentists, Aboriginal Health Services, community controlled organisations, community and palliative care services.

HEAD AND NECK CANCER PATHWAY

Purpose

The South Australian (SA) Head and Neck Cancer Pathway was developed through a collaborative effort by head and neck cancer specialist practitioners, generalist staff and consumers, under the auspices of the SA Cancer Clinical Network. It outlines requirements and recommendations for the management of patients with head and neck cancer, based on current evidence for the provision of best practice and consistent care.

The pathway is a statement of consensus based on current evidence and accepted approaches to the management of head and neck cancer. Recommendations should be followed subject to the health professional’s independent medical judgment and the patient’s preference in each individual case.

It should be noted that not all patients will progress through each step of the pathway. This is a consequence of many factors, including disease outcomes, management decisions and patient decisions.

Scope

The requirements and recommendations outlined in this pathway relate predominately to squamous cell carcinomas (SCC) of the larynx, oral cavity, oropharynx and hypopharynx, as these are the tumour sites with the highest incidences.

The pathway document has several appendices which summarise the pathology of the rare tumours of the skull base, nasopharynx, paranasal sinus, salivary glands, and thyroid. However their specific management is not detailed further in this document. Various international guidelines are available to guide treatment for these rare tumours (e.g. National Institute for Health -NICE, National Comprehensive Cancer network-NCCN) and the reader should refer to them for more detail.
Navigating the pathway

The following icons are used in this pathway.

The **'red-flag'** indicates signs and symptoms for earlier detection to expedite referral, treatment and access to supportive care, and maximise quality of life of persons diagnosed with head and neck cancer.

The `GP icon` indicates parts of the pathway of particular relevance to general practitioners.

**SOUTH AUSTRALIA CANCER PATHWAY KEY PERFORMANCE INDICATORS**

The SA Cancer Pathway Key Performance Indicators (KPIs) are drawn from the state-wide Performance Indicator Framework for SA Cancer Services (2010). These overarching KPIs provide a standardised framework for annual reporting by Local Health Networks to the SA Cancer Service.

- 100% of patients with an urgent new cancer referral from their general practitioner (GP) see the specialist within 2 weeks.
- 100% of patients diagnosed with cancer have documented clinical staging.
- 100% of patients are offered enrolment in clinical trials where available.
- 100% of patients commence treatment within 42 days of confirmed tissue diagnosis.
- 100% of patients who are admitted to hospital have an advance care directive.
- 100% of patients have a treatment summary (or discharge summary) sent to their nominated GP within 2 days of completion of the treatment episode.
- 100% of relapsed/progressive disease patients have a documented multidisciplinary care plan resulting from a multidisciplinary team meeting.
- 100% of patients have a documented survivorship plan on completion of treatment.
KEY RECOMMENDATIONS

The four key recommendations presented here reflect the priorities and strategic direction of the SA Head and Neck Cancer pathway in developing a quality service for patients with head and neck cancer, their families and carers in South Australia.

A complete list of recommendations relating to the diagnosis, treatment and supportive care of patients with head and neck cancer in South Australia are included at the end of each section, and in Appendix A.

<table>
<thead>
<tr>
<th>Pathway recommendation</th>
<th>Service / system recommendation</th>
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<tr>
<td><strong>Every person diagnosed with head and neck cancer should have an identified cancer care</strong></td>
<td>&gt; Patients with head and neck cancer should have their cancer journey streamlined by appropriate triage of referrals according to urgency of need. Appointments should be organised by a recognised coordinator, who will facilitate referral for supportive care from diagnosis throughout the treatment course.</td>
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<td><strong>coordinator along the continuum of care to ensure that care aligns with pathway recommendations.</strong></td>
<td>&gt; The numbers of head and neck cancer patients are monitored, and identification of service delivery gaps in care coordination is undertaken for each service through the development of a Checklist of Care.</td>
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<tr>
<td><strong>Establish and maintain state-wide systems for the collection and analysis of head and neck cancer patient data.</strong></td>
<td>&gt; Develop a SA state-wide integrated data base that captures minimum data of all persons with a diagnosis of head and neck cancer. An annual audit documents an overview of head and neck cancer services in SA.</td>
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<td></td>
<td>&gt; Multidisciplinary team members should be adequately supported to enable data collection for dataset items to be submitted for audit purposes.</td>
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<td>&gt; Maintaining a complete database of head and neck cancer cases will assist with the development of local evidence and research, and outcomes relevant to the local population.</td>
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<td></td>
<td>&gt; All treatment outcomes based on subtypes of head and neck cancer are reported, reviewed and measured. Multidisciplinary team members should ensure that they have a mechanism in place to capture any patients whose treatment is carried outside the multidisciplinary team.</td>
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<td></td>
<td>&gt; Initiate a process for centralised review and reporting of Key Performance Indicators (KPIs) and benchmarks of both clinical and service outcomes.</td>
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<tr>
<td>Pathway recommendation</td>
<td>Service / system recommendation</td>
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| **A state-wide standard approach to assessment using validated screening tools for** | ➤ Standardise evidence-based assessment tools to be used across health settings for managing head and neck cancer patients.  
➤ Early referrals to allied health professionals to maximise wellness and to promote self-management strategies and resources.  
➤ Assessment is undertaken at key points according to need to support primary health, community engagement and hospital avoidance. |
| **evaluating supportive care needs and functional status of persons with head and neck** |                                                                                                  |
| **cancer.**                                                                          |                                                                                                  |

| **A state-wide standard approach to improving equity and funding strategies for**     | Supportive care needs include:  
➤ dental care  
➤ nutritional assessment and enteric feeds  
➤ resource equipment (e.g. tracheostomy equipment, laryngectomy resources)  
➤ wound care products. |
| **supportive care needs of persons with head and neck cancer.**                      |                                                                                                  |
1. INTRODUCTION

Comprehensive cancer pathways provide evidence-based recommendations to guide best practice and consistent care in the management of patients diagnosed with cancer in South Australia.

1.1. ABOUT CANCER PATHWAYS

Comprehensive cancer pathways improve and standardise cancer care for all South Australians regardless of their location, origin, age or financial status. The pathways encourage the integration of clinical and supportive care with the associated considerations and key requirements for providing cancer services in SA.

Each cancer pathway is developed to guide delivery of optimal and consistent care and support of cancer patients and their families across SA. Each pathway is underpinned by the key principles of cancer care:

- patient-centred care
- safe and high-quality care
- multidisciplinary care
- supportive care
- care coordination.

Further information on the key principles of cancer care is provided in Appendix B.

Cancer pathways and their recommendations have been developed for the guidance of:

- **health professionals involved in the management of patients with cancer**; including public and private health professionals, general practitioners and dental practitioners

- **SA Health**, the Cancer Clinical Network Steering Committee (CCNSC) and associated committees and working groups

- **local health networks** in South Australia including: Country Health SA Local Health Network; Central Adelaide Local Health Network; Northern Adelaide Local Health Network; Southern Adelaide Local Health Network; and Women’s and Children’s’ Health Network

- **Aboriginal community-controlled health services**

- cancer care projects

- stakeholders at **non-government organisations** (NGOs).
Aboriginal and Torres Strait Islander Companion Document to the Statewide Cancer Control Plan

There is a significant difference in the burden of cancer for Aboriginal and Torres Strait Islander people in Australia due to poorer identification of cancer, higher incidence of preventable cancers, and higher comorbidities that can limit treatment options.

The Aboriginal and Torres Strait Islander Committee of the SA Cancer Clinical Network has developed an Aboriginal and Torres Strait Islander Companion Document to the Statewide Cancer Control Plan (2011–2015) and Cancer Care Pathway, to provide clear direction on approaches to improve outcomes for Aboriginal and Torres Strait Islanders in South Australian with a cancer diagnosis.

The Aboriginal and Torres Strait Islander Companion Document to the Statewide Cancer Control Plan (2011–2015) provides further information and context to the issue of cancer. For full details, visit www.sahealth.sa.gov.au.

1.2. INTRODUCTION TO THE SOUTH AUSTRALIAN HEAD AND NECK CANCER PATHWAY

The SA Head and Neck Cancer Pathway is a guide to the optimal management and care of patients diagnosed with predominately squamous cell head and neck cancers. This pathway is a statement of consensus based on current best practice, evidence and accepted approaches to the treatment and management of head and neck cancer. It has been developed through a collaborative effort of a wide range of health professionals including head and neck cancer specialists, generalist staff and consumers.

Aims of the SA Head and Neck Cancer Pathway

> To provide guidance and consistency of practice in patient management and to reduce the variation in current practice observed throughout South Australia
> To encourage early, appropriate referral and early diagnosis in the general population and in high risk groups
> To support information provision and decision making tailored to patient’s needs
> To encourage provision of psychosocial care, including assessing and responding to emotional, psychological, spiritual, social and familial requirements
> To ensure that all patients with head and neck cancer are offered the best chance of cure or palliation irrespective of where they present or are treated.
> To optimise coordinated care delivery for head and neck cancer patients at all stages of their disease.
> Particular attention needs to be paid to the specific needs patients from regional and remote South Australia, and patients from culturally and linguistically diverse backgrounds.

The pathway promotes a consistent and standardised approach to managing care, to ensure that people affected by head and neck cancer experience coordinated care.

People affected by head and neck cancer have diverse and complex clinical and supportive care needs. Figure 1.1 illustrates the optimal care requirements and recommended timeframes for patients with head and neck cancer. It is acknowledged that many people affected by head and neck cancer may not follow every step of the pathway due to variations in clinical presentation that will influence individual decisions about patient care.
**Figure 1.1 Head and Neck cancer pathway flowchart**

**PREVENTION AND MINIMISING RISK**
- Promotion of healthy lifestyle (smoking cessation, healthy diet, healthy weight, limiting alcohol intake)
- Reducing risky behaviours (smoking cessation, ‘sun smart’ behaviours)

**PRESENTATION + EARLY DETECTION**
- Patient seeks advice/medical review of symptoms
- GP/Dentist recognises potential signs or symptoms of head and neck cancer
- GP/Dentist conducts initial assessment and initiate referral

**REFERRAL**
- Referral to a head and neck specialist or ENT department (referral confirmed within 24 hours)
- The most rapid form of referral technology should be used (e.g. Enterprise Patient Administration System or EPAS)
- Identified diagnostic tests booked

**DIAGNOSIS + STAGING**
- Diagnostic and histopathological investigations
- Assessment for fitness for treatment at High Risk Clinic
- Allied health assessment for pre-treatment supportive care needs
- Specialist dental treatment

**PRESENTATION AT MULTIDISCIPLINARY TEAM (MDT) MEETING**
- Assessment of diagnostic investigations and pre-treatment assessments
- Staging recommendation
- Individualised treatment recommendations
- Feedback to GP, patient and family
- Referral to other allied health workers as required

**TREATMENT**
- Surgery/ chemotherapy/ radiotherapy
- Clinical trials
- Supportive care
- Complementary therapies

**FOLLOW-UP**
- Systematic post-treatment surveillance by care coordinator
- Discussion at MDT meeting

**PALLIATIVE CARE**
- Patient-centred approach
- Referral to specialist care services

**SURVIVORSHIP**
- Long-term monitoring
- Transition to primary care

**DISEASE RECURRENCE**
- Reassessment of disease status
- Referral back to MDT

**TRANSITION TO END OF LIFE CARE**
- 100% of patients have a documented survivorship plan on completion of treatment
1.3. FURTHER INFORMATION

➢ **Appendix C:** Patient Information Pathway provides an expanded view of the typical pathway for patients with head and neck cancer in the SA Health system. The information provides details for patients on the type of intervention to expect, and services available.

➢ **Appendix D:** Recommended Key Performance Indicators (KPI's). This represents the priority performance measures required to close the gaps in current head and neck cancer care.
2. HEAD AND NECK CANCER IN SOUTH AUSTRALIA

Head and neck cancers are invasive tumours that originate in mucosal cells that line the upper aerodigestive tract. The majority of head and neck cancers are squamous cell tumours.\(^2\) Tobacco and alcohol use are major risk factors for the development of head and neck cancers.\(^3\) Other risk factors include sun exposure, and human papillomavirus (HPV).

2.1. INCIDENCE AND TRENDS

Head and neck cancers have a relatively low incidence in SA, accounting for approximately 2% of all new cancer cases diagnosed each year.\(^4\)

In 2007, the incidence rate for head and neck cancers among South Australians was 8.6 cases per 100,000. Incidence rates were higher in men than women, with 106 new cases of head and neck cancer reported in men compared with 53 new cases in women.\(^3\)

Incidence rates for head and neck cancers have been increasing in both men and women since 1977 (Figure 2.1). Between 2003 and 2007, incidence rates for head and neck cancers in SA increased by 5.2%. The increase in incidence rates is expected to continue as the population of Australia ages.

Figure 2.1 All head and neck cancers by 10-year date range

![Graph showing incidence of head and neck cancers by 10-year date range]

Source: SA Health Cancer Registry. Last updated by Epidemiology branch, SA Health- 24 February 2012

Trends are present in the incidence of specific types of head and neck cancers. Data spanning 1977–2007 from the SA Health Cancer Registry show:

- a decrease in the incidence of laryngeal cancer
- an increase in the incidence of oropharangeal cancers (Figure 2.2).

The increased incidence of oropharangeal cancers is increasing in women and younger men. Given the role that human papilloma virus (HPV) has in the aetiology, this trend may reflect an increase in
potentially HPV-associated oropharyngeal cancer in Australia between 1982 and 2005.5

Figure 2.2 All head and neck cancers – average incidence rate by 10 year trends

![Graph showing the average rate of incidence by 10 year trends for various head and neck cancers.](source)

Source: SA Health Cancer Registry. Last updated by Epidemiology, SA Health- Feb 2012

Cancers of the lip and pharynx (excluding the nasopharynx) appear to be more common in regional rural areas, and more frequently occur on the lower lip and among males.3

Despite its relatively low incidence, the disease burden of head and neck cancer is significant. Due to under-recognition of symptoms in the early stages, patients often present with more advanced disease requiring more complex and intensive multi-modality treatments and rehabilitation.

2.2. MORTALITY AND SURVIVAL

In 2007, there were 898 deaths from head and neck cancers in Australia, accounting for 2.3% of all cancer deaths.2 Limited data are available to report any state-based trends in the mortality rate from head and neck cancers in SA.

In 2008, the survival rate from head and neck cancers was reported as 86% at 1 year post-diagnosis and 63% at 5 years post-diagnosis (Figure 2.3). An individual’s prognosis depends on the type and stage of head and neck cancer, as well as their age and general health at time of diagnosis.
Internationally, some marginal improvements in survival from head and neck cancer have been reported. However, overall there has been no significant improvement in outcome in head and neck cancer for three decades.\(^5\)

Marginal improvements in survival rates for oropharangeal cancer may be attributed to:

- the increased in HPV-related oropharyngeal squamous cell carcinoma (which generally affects a younger population group, often with no smoking association)
- improved imaging that have become increasingly available allowing better delineation and staging of disease which then has a favourable impact on treatment decisions and outcomes.\(^6\)

2.3. ABORIGINAL AND TORRES STRAIT ISLANDER POPULATIONS

The overall incidence of head and neck cancer in Aboriginal and Torres Strait Islander populations of SA and Northern Territory (NT) appears to be lower than the incidence on the non-Indigenous population. However, there is increasing evidence to show Aboriginal and Torres Strait Islanders with head and neck cancer have higher morbidity and mortality rates than their non-Indigenous counterparts. The South Australian Epidemiology department notes that current data may under-report Indigenous morbidity and mortality data.\(^7\)

This disparity may be due to higher nicotine and alcohol intake, younger presentation, delayed diagnosis, advanced disease at diagnosis, and lower completion rates of cancer treatment.\(^8\)

In contrast, local studies at the Royal Adelaide Hospital (RAH) have suggested that survival outcomes, standardised for stage and ability to complete therapy are as good if not better for Aboriginal and Torres Strait Islander populations.
Trends are present in the incidence of specific types of head and neck cancers within the Aboriginal and Torres Strait Islander population.

> The incidence of intra-oral and pharyngeal cancers is approximately three-and-a-half times higher for people from Aboriginal and Torres Strait Islander communities compared with non-Indigenous South Australians.\(^9\)

> In 2003, cancer of the oral cavity was reported to be the fifth most common cancer in people from Aboriginal and Torres Strait Islander communities in South Australia and was not ranked in the top ten for non-Indigenous South Australians.\(^10\)

Poorer outcomes for Aboriginal and Torres Strait Islander populations in SA and NT may be attributed to:

> poorer access to specialised head and neck cancer treatment in remote populations\(^11\)

> cancer being found at a more advanced state of progression.\(^12\)

### 2.4. ETHNIC AND SOCIOECONOMIC DIFFERENCES

Limited data and a small sample size make it difficult to demonstrate an association between ethnic and socioeconomic differences and head and neck cancers in SA. There is a non-significant trend for reduced survival in country patients versus metropolitan patients.

Internationally, an association between the incidence of head and neck cancer and lower socio-economic status (with lower education and income levels) has been demonstrated. There are established links between perceived health status, lifestyle, diet, access to preventative healthcare (particularly dental care), and the incidence of head and neck cancer.\(^13\)

Research indicates that social deprivation can be partly attributed to the incidence of squamous cell carcinoma of the oral cavity. Tobacco and alcohol is often used as coping mechanisms for dealing with disadvantage in income, housing, education, and family supports.\(^14\) Research is ongoing in this area.

### 2.5. FURTHER INFORMATION

> South Australia Cancer Registry of the Department of Health, South Australian Government


### RECOMMENDATIONS

> Service providers should promote the use of culturally appropriate health preventative information (e.g. smoking cessation) available from Aboriginal Health Council of South Australia, and Aboriginal and Torres Strait Islander Liaison Unit at specific local hospitals
3. MULTIDISCIPLINARY AND COORDINATED TEAM CARE

Multidisciplinary care is a team approach to health care that it is required for effective treatment planning and ongoing management of cancer.

3.1. OVERVIEW OF MULTIDISCIPLINARY CARE

A central component of multidisciplinary care is the multidisciplinary team (MDT) treatment planning meeting. MDT meetings, held face-to-face or via tele- or video-conference, bring together health professionals from diagnostic, treatment and support disciplines with relevant expertise to plan care or treatment for all patients. Membership of the MDT for head and neck cancer is discussed in Chapter 9.

Multidisciplinary care is essential for all patients, regardless of location (rural/metropolitan) or insurance status (public/private). A team approach facilitates enhanced interaction and coordination between health professionals involved in the care of patients with cancer, as well as increased patient satisfaction.

The approach to multidisciplinary care is underpinned by five core principles:15,16,17

- a team approach
- communication among team members
- access to the full range of therapeutic modalities for all patients, regardless of geographical remoteness or size of institution
- provision of care in accordance with agreed standards/pathway
- involvement of patients in decisions about their care.

Further information on benefits and principles of multidisciplinary care is provided in Appendix E.

3.2. ROLE OF THE GENERAL PRACTITIONER IN THE MANAGEMENT OF PEOPLE WITH HEAD AND NECK CANCER

GPs play an important role in the early detection, treatment and follow-up care of patients with cancer and in communication of prevention messages.

Early detection of cancer through recognition of symptoms, appropriate and timely referral to specialist care and establishment of partnerships with cancer specialists can ensure GPs play a critical role in the quality care, treatment and survivorship for cancer patients.

The role of the GP is paramount in the clinical and supportive aspects of care outlined below.

A factsheet of relevant information for GPs is provided in Appendix F.
Clinical care\textsuperscript{18,19}

**Early detection, investigation and referral**
- Recognition of signs/symptoms
- Documentation of history and clinical findings
- Responsibility for initiating and review of results of initial investigations
- Use of GP diagnostic flow chart
- Prompt referral to appropriate specialist using GP referral form
- GPs may wish to attend and participate in MDT meetings

**Throughout treatment and post-treatment surveillance**
- Liaison with specialist, possible roles include:
  - patient assessment
  - pre-chemotherapy assessment,
  - haematological and biochemical status (particularly in rural areas)
  - monitoring of toxicities

**Post-treatment surveillance**
- Use of protocols that require regular tests/investigations
- Monitoring of symptoms, including prompt referral back to specialist
- Monitoring of long-term complications that arise from chemotherapy, radiotherapy and surgery, reviewing and referring to supportive cancer services as required

Supportive care\textsuperscript{17}

**Throughout treatment and post-treatment**
- Patients should be informed and educated of suspected diagnosis and possible treatment options
- Ensure rural/remote patients receive additional information regarding services
- All individuals, particularly those at high risk, i.e. economically disadvantaged, intellectually challenged, mental health issues, limited or no family support, culturally diverse populations, Indigenous populations, adolescent and young adult (AYA) or geriatric, and rural/remote locations should be provided on going psychosocial support and referral as required
- Ensure patients have access to supportive organisations
- Development of mental health plan and input from psychologist to assess for anxiety and other psychological symptoms

**Support for caregivers**
- Provide support to patient’s caregiver/s

**Palliative care and end-of-life**
- GP has a particular role in palliative and end of life care given their awareness of the whole person, the needs of the family and the context of their life\textsuperscript{17}

A full list of relevant information for GPs is provided in \textbf{Appendix F}.\textsuperscript{17}
3.3. OVERVIEW OF COORDINATED CARE

Patients with head and neck cancer should have their cancer journey streamlined by a recognised coordinator, who will facilitate referral for supportive care from diagnosis throughout the treatment course.

A range of models for cancer care coordination have been established in recent years, with a general consensus that coordinated care assists in ensuring safety and quality outcomes in health care.

Coordinated care can be provided by any health professional on the multidisciplinary team or other members of the hospital support staff. A coordinator provides a central contact point for patients with head and neck cancer, their family members and the treating team. Coordination critically underpins the delivery of appropriate care.

The provision of coordinated care can involve clinical and/or supportive care components, and requires:

- highly developed communication and psychosocial skills to recognise a patient’s non-clinical needs as well as problems directly associated with cancer treatment
- a strong knowledge base in the management of head and neck cancers
- knowledge of the system in order to streamline timely referrals, and focus on support and care for the patient throughout the head and neck cancer journey.

<table>
<thead>
<tr>
<th>Clinical care&lt;sup&gt;21&lt;/sup&gt;</th>
<th>Supportive care&lt;sup&gt;20&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; Coordination with other health professionals to streamline the patient journey</td>
<td>&gt; Providing timely and consistent information for patients and their families</td>
</tr>
<tr>
<td>&gt; Triage and coordination of investigations</td>
<td>&gt; Point of contact for patients along their cancer journey</td>
</tr>
<tr>
<td>&gt; Care consistent with evidence-based guidelines</td>
<td>&gt; Assessment and screening of patients for clinical and supportive needs and to identify people at risk of adverse clinical or psychosocial outcomes</td>
</tr>
<tr>
<td>&gt; Prompt referral to specialist, allied health and support services</td>
<td></td>
</tr>
</tbody>
</table>
3.4. FURTHER INFORMATION


- Helpline for referral to counselling, Cancer Council SA (or call 13 11 20): http://www.cancersa.org.au/aspx/Patient_information_and_resources.aspx#Counselling


- Chapter 10: Presentation at head and neck cancer MDT meetings

RECOMMENDATIONS

- Cancer Council resources, including the brochure ‘A multidisciplinary team approach to cancer care’, should be used as standard practice.

- All patients with a head and neck cancer diagnosis should have access to a head and neck cancer coordinator throughout their cancer journey. These roles should be incorporated on sites with a head and neck cancer MDT.
4. SUPPORTIVE CARE

Supportive care addresses the physical, emotional and practical needs of the cancer patient. Supportive care requires generalist and specialist health services to provide support to people with cancer and their families and/or caregiver/s. Collaboration between all members of the multidisciplinary team is essential and all needs must be addressed in a culturally and linguistically appropriate manner.

Further details on the principles of supportive care are provided in Appendix G.

Psychosocial support and referral to supportive care services is vital for all people in the community affected by cancer. Increased support maybe required for those with a number of risk factors such as a history of intellectual impairment or mental illness and/or economic disadvantage, people with little or no family or community support, others who may live in rural/remote locations along with indigenous and non-English speaking community members.

The provision of supportive care requires an initial assessment and identification of the patient’s specific needs. This is achieved through regular discussion and systematic review of the patient and their care givers. Regular reassessment is essential, as needs frequently change throughout the cancer journey.

A screening tool, such as the NCCN Distress Thermometer, can be used to identify any physical, emotional and practical factors that may be causing a patient to experience distress. A detailed assessment of supportive care needs should be conducted on patients at high risk of distress to help identify those who require more specific one-to-one intervention and follow-up.

Following assessment, patients should be referred to an appropriate supportive care professional, such as a specialist nurse, psychologist, allied health professional or social worker. This chapter of the pathway explores suggested management for common supportive care needs. Self-management strategies, such as relaxation techniques and meditation, may also be beneficial.

When required, it is important to ensure patients and their caregiver/s have access to, an interpreter, culturally appropriate resources and support.

4.1. PHYSICAL NEEDS

Cancer and cancer treatments can often cause a variety of physical side effects and changes to a patient’s physical appearance. Patients with physical supportive care needs require referral to a specialist nurse or to a community support group.

Fatigue

Fatigue is a common and debilitating side effect of cancer and its treatments. Many factors contribute to fatigue, including immobility, sleep disorders, poor nutrition and reduced performance status. It is often experienced along with treatable factors, such as pain, nausea, anxiety, anaemia, medication side effects and other health related co-morbidities.

Fatigue affects physical, recreational and social activities, and can lead to delays in treatment, dose reductions or even discontinuation of therapy. Some patients report that fatigue is extremely distressing and has a negative impact on quality of life – more so than other symptoms, such as pain, nausea and depression.
All patients should be screened for presence and level of fatigue at regular intervals using a simple validated tool, such as a visual analogue scale (VAS) 0-10 (0 no fatigue, 10 worst fatigue imaginable). Other tools can be used to measure the impact of fatigue.

Management of fatigue should target the contributing factors, with appropriate treatment and referral to appropriate specialists. Evidence has shown that exercise interventions can have the strongest therapeutic benefit. Patients should be encouraged to maintain physical fitness and functional mobility by participating in a regular exercise regime during and after treatment.

Provision of patient and family education about this symptom can allay anxiety.

Pain

Pain is common in patients with cancer, and can be described in terms of soft-tissue pain, bone pain or neuropathic pain.

It is vital to determine the underlying cause of pain in order to direct treatment. Interventions may include opioids, relaxation therapy, massage, and educational programs aimed at enhancing pain control. Radiotherapy is often helpful for localised pain, such as that associated with bone metastases or neural impingement.

Severe pain that is difficult to control generally requires specific pain management from acute and/or chronic pain specialists.

Important principles of pain management are outlined in the Therapeutic Guidelines Palliative Care Version 3, 2010.

Memory and cognitive disturbance

Patients treated with chemotherapy and radiation therapy may experience alterations in cognitive function. A baseline assessment of cognitive function is important to rule out subtle manifestations of metastatic disease and to identify the need for strategies such as repetition of information.

Fertility

Certain cancer treatments can affect a patient's fertility. The likelihood of infertility in males, and infertility and/or premature menopause in women should be addressed as a component of the education and informed consent prior to treatment commencing.

All patients of reproductive age or younger should have fertility preservation options discussed/offered. Sperm, ovarian tissue or egg banking may be suggested.

If pregnancy is an option for particular patients after treatment, it is important to ensure that counselling addresses the issue of a potential reduced timeframe of fertility.

Discussion and referral to social worker, gynaecologist, psychologist or psychiatrist may be appropriate.

Oral health

Chemotherapy for any cancer type, blood and marrow transplantation and radiation in the area of the head and neck can cause oral complications ranging from dry mouth to infections that can interrupt treatment regimens.

Close monitoring of oral health is recommended before, during and after treatment for cancer to reduce the severity of complications, optimise treatment and enhance patient quality of life.
Where oral health is of particular concern, for example in head and neck cancer treatment, collaboration and input from a special needs dentist is recommended as part of the Multidisciplinary team.

Further information about the role of a special needs dentist in the treatment of head and neck cancers is provided in Chapter 10.

4.2. EMOTIONAL NEEDS

Being diagnosed and treated for cancer can affect a patient’s emotional wellbeing. Patients experiencing high levels of emotional distress are at risk of developing symptoms including anxiety and depression. Referral to a psychologist or psychiatrist is likely to be appropriate.

Depression

Patients undergoing treatment for cancer may experience physical and emotional stress and may continue to feel exhausted and depressed for long periods. Depression is linked to poor quality of life, increased length of hospital stay and poor coping skills. Each of these issues affects morbidity outcomes.

Regular screening and ongoing monitoring for depression by health professionals as part of long-term follow-up care is required. Referral to a psychologist or psychiatrist may be appropriate.

Body image

Body image is the way a person feels about their appearance. Some cancer treatments can cause physical changes to a patient’s body, such as hair loss, scars from surgery, loss of a body part, changes to the skin, weight gain or weight loss. Physical changes can result in poor body image.

Patients should be provided with individualised and accurate information about any expected physical changes before treatment.

Support and counselling by a specialist psychologist, psychiatrist or social worker may assist patients to make appropriate treatment decisions that incorporate the potential effect on their appearance.

Sexuality

Sexuality encompasses not only the physical aspects of sexual function, but also refers to how people view themselves and express themselves sexually and how they believe others see them.

Some effects may be temporary, while others are permanent. Physical problems may include low libido, dyspareunia and impotence. Other issues affecting sexuality include coping with changes in appearance, low self-esteem and changes in roles and relationships. Issues of sexuality should be raised with all patients, and identification and referral to a counsellor with expertise in the area may be required.
4.3. PRACTICAL NEEDS

Patients experiencing social, financial or practical issues, or who have minimal social supports, require referral to a social worker or welfare worker.

Social, financial and practical needs

Patients may experience a range of social, financial and practical needs, including:

- additional costs related to meal preparation, aids to assist with cooking and enteric feeding may be significant
- patients travelling from rural and remote areas may require assistance with travel and accommodation, including assistance with the Patient Assistance Transport Scheme (PATS).

Referral to a social worker for further assessment and identification of appropriate funding support may be required.

Rural patients

Clinicians referring patients from rural and remote communities for treatment and support services need to ensure that the patient and their family members are informed about assistance for travel and accommodation costs.

A cancer care coordinator can provide a link to the multidisciplinary team for rural patients and specialist rural nurses can provide access to programs or interventions requiring psychological support. Remote technology providing patients with access to counselling, and enhancement of skills of rural nursing staff have been demonstrated to improve psychological support.

Advanced Care Planning

Advanced care planning allows people make their preferences for important health care and personal decisions known in the event that they lose decision-making capacity.

Advanced care planning should be discussed with patients following a cancer diagnosis and early in the course of their disease. Advanced care planning may involve:

- discussing prognosis and possible future scenarios
- appointing of a substitute decision maker, and involving this person in on-going discussions
- deciding on current and future goals of care
- discussing patient choice for place of care
- documenting all discussions in an easily retrievable format.

Patients should be supported to discuss life goals, values and personal views and choices about their preferred outcome of care with a trained professional, family and/or close friend.
Communicating with patients and carers

Patients and their carers require both verbal and written information to assist them in understanding details about the disease, reasons for and likely effects of diagnostic procedures, treatment options (including known risks and potential adverse effects), preventative actions, and information about effective coping strategies.

This information should be culturally appropriate, and individualised where possible. People for whom English is not a first language may require access to a qualified interpreter during verbal communication.

It is recommended that health professionals ask patients whether they want additional information and discuss how much they wish to be involved in decisions about treatment. Family members, carers and/or others should be encouraged to attend consultations to provide support. Specific instructions for self-care may help patients and family members to maintain their desired level of independence throughout the cancer care journey.\(^\text{37}\)

All health professionals involved in a patient’s care should know what information has been given to the patient. A record of information provided, along with the patient’s preferences for information and involvement in decision-making, should be included in the notes and given to the patient’s GP, together with a comprehensive summary of the management plan. Communication needs to be effective, with fast and efficient links between hospitals and primary care teams.\(^\text{38}\)

4.4. RESPECTING DIVERSITY

People from Aboriginal and Torres Strait Islander backgrounds

People from Aboriginal and Torres Strait Islander backgrounds represent approximately 2% of the South Australian population.\(^\text{39,40,41}\) Just over half live in rural and remote areas, particularly areas to the north of Adelaide.\(^\text{32}\) This number is approximately double the state average of 25% for all South Australians.\(^\text{32}\)

Aboriginal and Torres Strait Islander people are more likely to present with advanced illnesses and may have multiple co-morbid illnesses in addition to cancer. Aboriginal and Torres Strait Islander people also have unique supportive care considerations associated with their cultural concept of health and wellbeing, needs for the delivery of health services, the involvement of family and community in health care and the cultural understanding of cancer.

The unique consideration for the care of Aboriginal and Torres Strait Islander populations are detailed in Box 4.1 overleaf.
Box 4.1 Considerations for the care of Aboriginal and Torres Strait Islander populations

**Aboriginal and Torres Strait Islander people have an holistic view of health and wellbeing**

- Health and wellbeing encompasses all aspects of physical, emotional, social, spiritual and cultural wellbeing and a specific kinship with family.\(^{42,43}\)
- There is a belief that wellbeing is determined socially, rather than biologically or pathologically.\(^{44,45}\)

**Structured and busy specialist clinical services may not cater well for the cultural needs of Aboriginal and Torres Strait Islander people**

- This can contribute to a broader sense of disillusionment, indifference and apathy.
- Adherence to unfamiliar treatments that have unpleasant side effects may be poor, especially when there are competing pressures to meet community responsibilities.
- Without cultural and allied support, patients can become lost in unfamiliar health service environments they do not understand and where their needs are poorly understood.

**Many Aboriginal and Torres Strait Islander people experience discomfort with health professionals of the opposite gender**

- There are divisions in the roles of ‘men’s and women’s business’, including differences from western values in relation to reproduction and sexuality.\(^{46}\)
- For example, it is often not appropriate for Aboriginal and Torres Strait Islander men to discuss any part of their body in the presence of a woman.\(^{47}\)

**Family and community involvement in health decision making is of paramount importance in Aboriginal and Torres Strait Islander culture**

- Aboriginal and Torres Strait Islander culture places a high importance on kin, with holistic, family-based care being valued over segregated care.\(^{48}\)
- Aboriginal and Torres Strait Islander health is more a collective consideration about family and community.\(^{49,50}\)

**Many Aboriginal and Torres Strait Islander people have a strong sense of home, and value being at home or close to home, particularly when ill**\(^{40}\)

- Aboriginal and Torres Strait Islander people have strong links to the land and a sense of ‘home’.\(^{51}\)
- This connection can be strong regardless of whether they are living a culturally-traditional lifestyle in remote locations, or in urban areas.
- Some patients may be reluctant to leave their community for treatment, even though this care may only be available in a remote urban setting.\(^{44}\)

**The concept of cancer may be poorly understood by some Aboriginal and Torres Strait Islander people, leading to a number of misconceptions**

- It is notable that there is no word meaning ‘cancer’ in most, if not all Aboriginal and Torres Strait Islander dialects. Unlike many other illnesses, the concept of cancer is not embedded in traditional Aboriginal and Torres Strait Islander story-telling.\(^{42}\)
- While cancer ‘spreading’ is widely understood, there is commonly a difficulty in understanding biomedical cancer language and pathology terminologies.\(^{42}\)
- Common misconceptions are that cancer is contagious, only effects non-Aboriginal people, is curable without treatment, and that western treatment is ineffective.\(^{42,52}\) It is commonly believed that a diagnosis of cancer is a death sentence, and that cancer is not treatable.
When managing the health care of Aboriginal and Torres Strait Islander people, it is important to include the input of those who are familiar with the Aboriginal and Torres Strait Islander culture and language. Staff with specific expertise in the management and support of Aboriginal and Torres Strait Islander patients are located in the larger metropolitan public hospitals. Aboriginal health nurses and Aboriginal hospital liaison workers are available to provide assistance following patient referral by the multidisciplinary team.

Engaging cultural and allied support can:

> help Aboriginal and Torres Strait Islander people navigate unfamiliar health service environments
> provide advice on culturally safe and respectful care to MDTs
> assist in understanding of the needs of Aboriginal and Torres Strait Islander people residing in rural and remote areas.

Culturally and linguistically diverse communities

Australia has one of the most culturally diverse communities in the world. In 2011, one in four of Australia’s population was born outside of Australia. It is therefore essential to consider the culturally and linguistically diverse needs of all people in relation to diagnosis, treatment and management of cancer.

All patients are individuals and require a person-centred approach to care. Health professionals should engage in respectful enquiry about preferences that intersect with health care, including religious or spiritual values, cultural values, gender preferences and dietary requirements. These aspects are connected to a successful health care experience and outcomes.

Within the culturally and linguistically diverse community, language barriers and lack of knowledge of the South Australian health care system limit access to health information and health care services.

The unique consideration for the care of culturally and linguistically diverse populations are detailed in Box 4.2.

**Box 4.2 Unique consideration for the care of culturally and linguistically diverse populations**

<table>
<thead>
<tr>
<th>People may have a variety of cultural perspectives or preferences, including:</th>
</tr>
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<tbody>
<tr>
<td>&gt; patient preference to see a medical professional of their own sex</td>
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<tr>
<td>&gt; myths and misconceptions about cancer diagnosis</td>
</tr>
<tr>
<td>&gt; cancer may be a taboo subject perceived to cause discrimination, contamination, shame or retribution</td>
</tr>
<tr>
<td>&gt; religion may play a fundamental role in the person’s attitude towards their disease and treatment</td>
</tr>
<tr>
<td>&gt; patients may have perceptions attributed to pain and suffering</td>
</tr>
<tr>
<td>&gt; family and extended family have a central role in many cultures. Family members often share rights and responsibilities for decision-making and this may influence the choice of treatment.</td>
</tr>
</tbody>
</table>

Attitudes to caring and support may vary between and within cultures. It is important for health professionals not to make assumptions or stereotype individual patients.

Patients should be encouraged to seek support from family and friends, and from community, ethnic and religious organisations, if appropriate. Regardless of cultural background, wherever possible,
patients should be offered the opportunity to bring a family member or friend with them to consultations and treatment. People may not be accustomed to the concept of support from external agencies, so this requires a sensitive and respectful approach.

4.5. FURTHER INFORMATION

- Appendix H lists key cancer resources and support groups in South Australia
- Appendix I outlines the process for referral of patients to psychosocial care
- Cancer Voices South Australia, a volunteer organisation that serves as a consumer advocate for people living with cancer: http://www.cancervoicessa.org.au/
- National Comprehensive Cancer Network (NCCN), Clinical Practice Guidelines in Oncology Cancer-Related Fatigue: www.nccn.org
- Bolimos M, 2009, Coping with cancer related tiredness (fatigue), published by the Royal Adelaide Hospital (Occupational Therapy Department and Cancer Centre)
- Eastern Cooperative Oncology Group assessment tool: http://ecog.dfci.harvard.edu/general/perf_stat.html
- Chris O'Brien Lifehouse at RPA, An everyday guide to living with cancer in Australia, includes a detailed Support Directory: http://www.lifesupportmagazine.co.au
- Cancer Council SA, Cancer Helpline: 13 11 20

RECOMMENDATIONS

- Health professionals should be trained in supportive care screening to encourage inclusion of supportive care issues as part of multidisciplinary care.
- The NCCN Distress Thermometer in automated electronic (touch-screen) format may be used to screen patients with results scored and transcribed so that information is readily available to guide the consultation. QUICATOUCH has been found to be effective in monitoring patients and increasing the number of new patients receiving timely and appropriate psychological treatment.
- Patient diaries should be implemented as standard care as a means of providing practical information about head and neck cancer treatment. Use of patient diaries requires continual qualitative evaluation that includes consumer involvement.
- The use of health-related quality of life (HRQOL) measures in clinical practice, such as the University of Washington Quality of Life version 4 (UWQOLv4), is recommended.
5. SUPPORTIVE CARE NEEDS OF PATIENTS AFFECTED BY HEAD AND NECK CANCER

The supportive care needs of patients with cancer vary in complexity and severity along the disease trajectory. Some supportive care needs are common to many cancers (See Chapter 4), while others are specific to head and neck cancers.

Patients with head and neck cancer can experience a number of side effects that result in specific physical, psychosocial, nutritional and communication supportive needs.

Patients with head and neck cancer can experience a number of side effects that may alter their quality of life. Side effects may be exacerbated by local or systemic treatments, and require specific supportive care interventions.

The multidisciplinary allied health and nursing team work closely together to support patients with head and neck cancer. It is essential that there are established systems for communication and information sharing between all team members.

Specialist supportive care for patients with head and neck cancer may be provided by:

- dietitians
- speech pathologists
- physiotherapists
- occupational therapists
- specialist nursing staff.

5.1. SPECIFIC SUPPORTIVE CARE NEEDS FOR PATIENTS WITH HEAD AND NECK CANCER

Speech and communication

Voice, speech and swallowing can be affected by head and neck cancers and by the type and/or combination of treatment modalities.

Communication and/or swallowing impairments (dysphagia) can affect day-to-day activities. There is a strong association between communication/swallowing difficulties and poorer QoL for patients as well and their families and/or care givers.57

As a core member of the head and neck MDT, the speech pathologist can liaise closely with team members and advocate for treatment and interventions to achieve best functional outcomes for impairments in communication and swallowing.

The speech therapy supportive care interventions for people with head and neck cancer at different stages of the cancer journey are outlined in Table 5.1.
Table 5.1 Speech Therapy supportive care interventions

<table>
<thead>
<tr>
<th>Pre-treatment</th>
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</thead>
<tbody>
<tr>
<td>&gt; Pre-treatment counselling is recommended.</td>
</tr>
<tr>
<td>○ The speech pathologist should provide the patient with realistic expected short and long-term speech voice and swallow functions so that they are</td>
</tr>
<tr>
<td>prepared to manage these deficits when they occur.</td>
</tr>
<tr>
<td>○ Detailed information on voice restoration options is recommended for all patients undergoing laryngectomy. This supports these patients to select</td>
</tr>
<tr>
<td>the best voicing option to suit their lifestyle.</td>
</tr>
<tr>
<td>&gt; Pre-treatment communication and swallowing evaluation is recommended, and is an established part of the laryngectomy care pathway.</td>
</tr>
<tr>
<td>○ Pre-treatment communication and/or swallow assessments enable assessment of baseline function, initiate dysphagia management prior to treatment if</td>
</tr>
<tr>
<td>this is identified, and recognise those patients that are at higher risk for post treatment communication and/or swallowing impairment and/or long term</td>
</tr>
<tr>
<td>deficits.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>During treatment</th>
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<tbody>
<tr>
<td>&gt; Management of communication and swallow impairments during chemotherapy and radiation should be conducted by speech pathologists in conjunction with</td>
</tr>
<tr>
<td>nursing, dietetic and dental professionals.</td>
</tr>
<tr>
<td>&gt; Management aims to identify functional changes to speech and swallowing caused by treatment and implement exercises and other interventions to counteract these.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Post-treatment</th>
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</thead>
<tbody>
<tr>
<td>&gt; Patients should be <strong>provided with non-verbal communication methods in the post-operative period</strong> e.g. pen/paper and where appropriate computerised</td>
</tr>
<tr>
<td>voice output communication aids</td>
</tr>
<tr>
<td>&gt; Patients should receive ongoing assessment and review of speech, voice, and swallowing function</td>
</tr>
<tr>
<td>&gt; In liaison with medical teams, a speech pathologist should commence of oral motor, speech and swallow rehabilitation exercise protocols in an attempt to</td>
</tr>
<tr>
<td>maintain range and mobility of the structures required for voice, speech and/or swallowing.</td>
</tr>
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<table>
<thead>
<tr>
<th>Follow-up care</th>
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<tbody>
<tr>
<td>&gt; Follow-up care may continue for many years depending on individual need.</td>
</tr>
<tr>
<td>&gt; Patients from rural areas should receive ongoing assessment and review of speech, voice and swallowing therapy and protocols.</td>
</tr>
<tr>
<td>&gt; There should be strong communication links between rural and central treatment centres, concerning complex or problematic surgical voice restoration, or</td>
</tr>
<tr>
<td>changes in patient's communication or swallowing function over time. Any concerns should be communicated to central treatment centres via the treating speech</td>
</tr>
<tr>
<td>pathologist or head and neck cancer care coordinator.</td>
</tr>
</tbody>
</table>
Nutrition and weight loss

Between 30% and 50% of patients with head and neck cancer are nutritionally compromised on initial presentation, and between 80 and 90% of patients lose a significant amount of weight during multimodality treatment.

Weight loss and malnutrition in people with head and neck cancer has significant adverse effects on infection rates, treatment response, treatment interruptions, health care costs resulting from unplanned admissions and increased length of stay (LOS), and decreased patient quality of life (QoL).

Nutritional outcomes and QoL of patients with head and neck cancer have been shown to improve with frequent dietetic contact. Dietitians should active members of the head and neck MDT and should be involved before, during and after treatment.

The role of a dietitian in the management of patients with head and neck cancer is to:

- conduct ongoing nutritional assessment
- advocate for appropriate nutritional intervention
- develop individualised nutrition care plans to meet patients’ daily nutritional requirements
- provide practical, responsive and culturally appropriate nutritional information on strategies to achieve dietary requirements via oral/enteral routes
- provide advice on effective management of acute/chronic treatment toxicities affecting oral intake, and refer to appropriate specialists for medical management as required
- ensure general practitioners, patients/carers and community/rural based Dietitians and cancer nursing staff receive updated communication of nutrition care plans and ongoing support to administer and manage oral/enteral nutrition.

The dietetic pathway for people with head and neck cancer is detailed in Appendix J. A further dietetic pathway for people with head and neck cancer who received adjuvant radiotherapy and or chemotherapy is detailed in Appendix K.

The nutritional supportive car interventions for people with head and neck cancer at different stages of the cancer journey are outlined in Table 5.2.

**Table 5.2 Nutritional supportive car interventions**

<table>
<thead>
<tr>
<th>Pre-treatment</th>
<th>Nutritional screening should be undertaken on all patients at diagnosis using a validated nutrition screening tool (by nursing, medical or other staff) to identify patients who are malnourished or are at high risk of malnutrition.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nutrition assessment should be conducted by the Dietitian on referral using a validated nutrition assessment tool, such as the Patient-generated Subjective Global Assessment (PG-SGA) or Subjective Global Assessment (SGA).</td>
</tr>
<tr>
<td></td>
<td>All head and neck patients receiving radiotherapy require automatic referral to the Dietitian for pre-treatment nutrition assessment. These patients may not present malnourished at baseline, however are identified as having future high nutritional risk and consequently require automatic dietetic referral and consideration of appropriate nutrition support.</td>
</tr>
<tr>
<td>During treatment</td>
<td>Repeat nutrition screening should occur at intervals through each stage of cancer treatment.</td>
</tr>
</tbody>
</table>
> **Weight should be recorded at least weekly** for all inpatients, and recorded at each outpatients visit. A weight loss of >2kg within a 2 week period requires prompt referral to the Dietitian. ⁸⁷

### Post-treatment

> Following surgery, dietetic follow-up should occur with the **aim of maintaining and improving nutritional status**.

- For patients who are not receiving adjuvant radiotherapy/chemotherapy, dietetic follow-up should continue until the patient’s nutritional status is optimised and stable. Dietary advice should be adjusted to address cancer prevention diet and physical activity guidelines where appropriate, depending on the patients’ disease state and side effects.

- For patients who received adjuvant radiotherapy/chemotherapy, dietetic follow-up should occur fortnightly for six weeks after completion of treatment to address the acute treatment toxicities impacting on a patient’s oral intake, weight and nutritional status.

### Follow-up care

> It is recommended that head and neck patients receive dietetic follow-up for a minimum of 6 months post treatment or until chronic treatment toxicities no longer impact oral intake. Weight stability and nutritional status must be demonstrated to be maintained by oral diet alone with the cessation of all nutrition support (enteral nutrition/ oral supplements) prior to discharge from ongoing dietetic follow-up.

> Rural head and neck cancer patients require equitable access to expert head and neck dietetic follow-up post-treatment. To ensure this, expert head and neck Dietitians must be proactive in providing the appropriate dietetic training, education, resources, support and clinical updates to rural practising Dietitians to ensure ongoing evidence based care. ¹⁰⁹

### Palliation

> Referral to a dietitian for patients with end stage head and neck cancer should be made after consultation with the head and neck MDM (palliative care, medical, Speech Pathology) on the nature or progression of dysphagia, disease state and patient goals to determine the appropriate level of nutrition intervention required. ⁸⁸

Further information can be found in the [COSA Evidence based practice guidelines for the nutritional management of adults with head and neck cancer](#) which provides the framework for clinical dietetic management of patients with head and neck cancer throughout the continuum of medical care. ⁵⁸,⁵⁹,⁶⁰

### Head and neck lymphoedema

Up to three-quarters of patients with head and neck cancer develop late-effect lymphoedema. Early diagnosis and **quick referral to an occupational therapist or physiotherapist for treatment is needed to help reduce symptoms**.

The gold standard for lymphoedema management is based on the [Best Practice International Consensus in the Management of Lymphoedema](#).

Key elements of treatment include manual lymphatic drainage and simple lymphatic drainage. Deep breathing patterns with arm movements have been shown to help improve drainage into the left and right lymphatic ducts, and to the venous system. The efficacy of this approach remains to be proven, but it may provide psychological and symptomatic benefits.
Other specific supportive care needs

**Body image**

The rehabilitative process for patients with head and neck cancer can often be difficult because of the importance placed by society on physical appearance. The advanced stage of cancer that often occurs at diagnosis can pose a risk to the integrity of the face.\(^6\)

Supportive care needs for patients with poor body image is explored in Chapter 4.

A pre-treatment information session by an experienced speech pathologist is important for patients who require a laryngectomy.

**Special needs dentistry**

Surgery and radiotherapy for head and neck cancer can induce oral side effects requiring specialist dentist intervention.

Close monitoring of treatment side effects and their impact on dental health requires collaboration and input from a special needs dentist. The special dental treatment for patients is explored further in Chapter 10.

5.2. FURTHER INFORMATION

- **Appendix J**: Head and neck cancer dietetic pathway
- **Appendix K**: Head and neck cancer dietetic pathway radiotherapy and/or chemotherapy
- Flinders Medical Centre, *Speech Pathology Evidence Based Guidelines*: available mid-2013
RECOMMENDATIONS

> Nutritional screening, referral processes and clinical practice during and post-treatment needs to be standardized across the public and private sector. All patients with head and neck cancer should be screened using the validated MUST screening tool on admission and in outpatients.

> All patients should have their weight recorded weekly as inpatients, and at each outpatient visit.

> At-risk patients should receive early nutritional intervention by a dietitian with experience in treating patients with head and neck cancer.

> Funding and access to home enteral nutritional (HEN) services should be equitable across greater metropolitan and rural South Australia

> A template should be developed to transfer information about supportive care needs of patients with head and neck cancer and their treatment plans at discharge. This includes transferring information between hospitals, to GPs and to community health staff. Ideally, this information should be available in electronic form and should provide up-to-date patient information for the head and neck MDT.

> Patients having surgery to the tongue, palate or larynx, or radiotherapy, should be referred to a speech pathologist for assessment of voice, communication and swallow.

> Dietetic and speech pathology resources required for best practice care of patients with head and neck cancer should be benchmarked. Long-term needs of patients and carers must be supported with adequate numbers of specialist staff.

> Acute sector health professionals should participate in professional development and mentoring programs for rural cancer care health workers. This may include: peer shadowing; telemedicine support; and contribution to competency-based training for rural speech pathologists and dietitians.

> Nurses working in oncology departments who are providing complex care for patients with head and neck cancer should have advanced standards and competencies in plastics, wound care and tracheostomy management. Oncology nurses working in radiotherapy day units should demonstrate a high level of clinical proficiency in a range of procedures, treatments and interventions that are evidence based, and based on Australian Nursing and Midwifery Council (ANMC) competencies.

> Tracheostomy equipment (e.g. humidification, suction, speech aids) may be required by patients for an extended period on discharge from hospital. Subsidised funding should be available for these resources. Patients should also be given a listing of sources from which equipment can be accessed in the community.
6. PREVENTION AND MINIMISING RISK

Cancer is one of the most common causes of morbidity and mortality in South Australia, accounting for more potential Years Life Lost (YLL) than any other condition.\textsuperscript{62}

Based on current incidence rates by age, at least one in three South Australians is diagnosed with cancer before 75 years of age.\textsuperscript{51}

6.1. CANCER RISK FACTORS AND PREVENTION

Cancer represents Australia’s greatest disease burden, ahead of cardiovascular disease. Cancer is a disease associated with ageing. With the number of people aged over 65 years set to double by 2051, cancer incidence is projected to continue rising.\textsuperscript{63}

Current evidence indicates that approximately one-third of cancer deaths in Australia can be attributed to known and avoidable risk factors. Appropriate prevention strategies have the potential to reduce cancer incidence.

### Risk factors

<table>
<thead>
<tr>
<th>The key <strong>modifiable risk factors</strong> for cancer are defined as the SNAPSS risk factors. These are:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Smoking/exposure to tobacco smoke</td>
</tr>
<tr>
<td>- Nutrition (concerns about poor diet/nutrition)</td>
</tr>
<tr>
<td>- Alcohol (risky alcohol consumption)</td>
</tr>
<tr>
<td>- Physical activity (inadequate exercise or being overweight)</td>
</tr>
<tr>
<td>- Sun exposure (exposure to harmful ultraviolet radiation)</td>
</tr>
<tr>
<td>- Stress.</td>
</tr>
</tbody>
</table>

### Prevention strategies

<table>
<thead>
<tr>
<th>Prevention and early detection strategies include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- promotion of healthy lifestyles (stopping smoking, healthy diet, healthy weight, limiting alcohol intake)</td>
</tr>
<tr>
<td>- reducing risky behaviours (stopping smoking, ‘sun smart’ behaviours).</td>
</tr>
</tbody>
</table>

6.2. MAJOR RISK FACTORS FOR HEAD AND NECK CANCER

**Tobacco smoking and alcohol** are major risk factors for head and neck cancer.

Known risk factors for head and neck squamous cell cancer include:

- tobacco smoking (cigarettes, pipes and cigars)
- excessive consumption of alcohol
- viral infections, including human papilloma virus (HPV16) seropositivity for cancers of lingual and palatine tonsils
- pre-existing oral lesions
- ultraviolet radiation for lip cancer
- age
- male gender.
Tobacco smoking and alcohol consumption

Tobacco smoking is associated with a ten-fold increase in risk of head and neck cancer, while a daily intake of 100g alcohol is associated with a six-fold increase. Tobacco and alcohol have a synergistic effect on risk of head and neck cancer.

It is important that anyone with lifestyle risk factors associated with head and neck cancer who presents with symptoms suggestive of a cancer of the head and neck is referred for appropriate investigation.

Human Papilloma Virus

The Human Papillomavirus (HPV) has been identified as an etiological agent for head and neck cancers – that is, HPV has been associated with the development of certain types of head and neck cancers. Approximately 35% of oral cancers are positive for HPV DNA, and 90–95% are positive for HPV-16. These cases tend to occur in younger men who do not smoke or drink alcohol, and have a favourable outcome.

Studies suggest an association between HPV-positive head and neck cancers and sexual behaviour, including increasing numbers of both vaginal and oral sex partners, and a history of genital warts. There is also a correlation between marijuana use and the risk of developing an HPV-16-positive head and neck cancer.

Research into transmission of oral and oropharyngeal HPV is only in early stages, and opportunities for risk reduction are not yet clear. An absence of clinically identifiable premalignant lesions means that screening is dependent on molecular biomarkers.

Pre-existing oral lesions

Pre-existing oral disease, such as leukoplakia, lichen planus, erythroplakia and submucosal fibrosis, have an increased risk of progressing to malignancy. Oral leukoplakia is the most common form of pre-malignant oral lesion, however several studies have found that only a small number of leukoplakias eventually progress to malignancy.

Oral patches with suspicious features, such as bleeding, should be referred promptly for appropriate assessment and biopsy by a head and neck cancer specialist. Many health professionals will offer treatment and surveillance within a multidisciplinary clinic.

Age and gender

About 90% of oral cancers occur in people in people older than 50 years of age. The incidence of oral cancers is also about two-thirds higher amongst men than women.

Aboriginal and Torres Strait Islander status

The incidence of oral cancer is about three times higher among Australians from Aboriginal and Torres Strait Islander communities compared with non-Indigenous Australians.

Identifying people who may be at higher risk of head and neck cancer enables the GP or other health professionals to develop a surveillance plan and/or monitor for symptoms that may require further investigation.

Tailored interventions are also required to reach and educate high risk groups because they generally constitute socially disadvantaged groups.
6.3. FURTHER INFORMATION


> SA Health, Cancer in Australia 2007, with projections to 2010:


> Drug and Alcohol Services South Australia: http://www.dassa.sa.gov.au

> DASSA web Link Aboriginal Services and Programs:


**RECOMMENDATIONS**

> Health promotion strategies should promote the importance of a healthy lifestyle for all South Australians.

> Aboriginal health services, Aboriginal Health Workers and health professionals working with culturally and linguistically diverse communities should be supported to promote interventions to encourage smoking cessation, reduction in high-risk alcohol intake, and promotion of regular ‘health’ or ‘dental’ checks.
7. SCREENING AND EARLY DETECTION

For many cancers, treatment outcomes and survival can be improved by finding and treating the disease at an early stage. Uptake of appropriate population-based screening programs and increased awareness of early detection measures can optimise outcomes following a diagnosis of cancer or a precancerous condition.\(^1\)

7.1. SCREENING

The term ‘screening’ refers to population-based testing of people who do not have symptoms of cancer and are not at high risk of cancer to identify signs of disease requiring investigation before symptoms are apparent. No formal screening programs for head and neck cancer currently exist.

7.2. SIGNS AND SYMPTOMS OF HEAD AND NECK CANCER

The signs and symptoms of head and neck cancer can include:

- hoarseness
- ulceration of oral/oropharyngeal mucosa
- persistent oral swellings
- red or red and white patches of the oral mucosa
- dysphagia
- unexplained tooth mobility not associated with periodontal disease
- non-healing dental extraction site
- unresolving neck masses
- cranial neuropathies, including unexplained facial weakness
- referred pain in the ear without evidence of local ear abnormalities
- orbital masses
- unilateral serosanguinous nasal discharge.

These signs and symptoms require prompt assessment by a GP, especially where symptoms persist for a number of weeks.

Improving community awareness

Improving community awareness about the signs and symptoms of head and neck cancers, and the importance of seeing a GP promptly would improve early detection and outcomes for people diagnosed with these cancers.

Community awareness may be improved through:

- promotion of 6–12 monthly dental and medical examinations with appropriate health questionnaires (such as skin, voice, oral symptoms, swallowing and behavioural assessments for risk factors)
- tailored education for high-risk groups, including communities with higher smoking rates, lower socioeconomic lifestyle and people from Aboriginal and Torres Strait Islander communities\(^2\)
- strategies to promote smoking cessation and prevention.\(^3\)
7.3. IDENTIFICATION AND REFERRAL OF PATIENTS WITH SIGNS AND SYMPTOMS OF HEAD AND NECK CANCER

Initial presentation

A patient presenting to a GP, dentist or hospital emergency unit with symptoms suggestive of head and neck cancer requires rapid access to assessment and appropriate investigations in order to minimise any delay in diagnosis.

- Urgent referral from a GP/Dentist to a head and neck cancer specialist should occur for patients presenting with the signs and symptoms of head and neck cancer (listed above) persisting for MORE THAN 3 WEEKS.
- Suspicion should be further raised if the symptomatic patient is a heavy smoker or heavy alcohol user, aged over 45 years, and/or male.

Information about assessment and investigation, and referral, is provided in the following sub-sections.

Assessment and investigation

Investigations may be undertaken after urgent specialist referral has occurred.

- The decision about which clinical investigations should be undertaken by the GP may require discussion (by phone or e-mail) between the GP and specialist (or senior ENT Registrar in public hospitals).
- No biopsy should be carried out in a non-specialist environment.

Investigations must not replace or delay urgent specialist referral; negative investigation findings (such as negative imaging) do not exclude the presence of head and neck cancer.

Table 7.1 provides an overview of initial assessments and investigations for patients presenting with symptoms of head and neck cancer.

Table 7.1 Initial assessment and investigations of symptoms of head and neck cancer

<table>
<thead>
<tr>
<th>Clinical assessment/investigation</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical presentation</td>
<td>Identify any of the following signs/symptoms:</td>
</tr>
<tr>
<td></td>
<td>&gt; change in voice, usually persistent hoarseness</td>
</tr>
<tr>
<td></td>
<td>&gt; non-healing oral lesions-mass or ulcer</td>
</tr>
<tr>
<td></td>
<td>&gt; dysphagia for solids</td>
</tr>
<tr>
<td></td>
<td>&gt; persistent sore throat, particularly if associated with otalgia</td>
</tr>
<tr>
<td></td>
<td>&gt; unusual oral bleeding or epistaxis</td>
</tr>
<tr>
<td></td>
<td>&gt; other non-specific features include: numbness of tongue or other area of mouth, and swelling of the jaws</td>
</tr>
<tr>
<td>Clinical assessment/investigation</td>
<td>Process</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td><strong>Case history</strong></td>
<td>Enquire about the following symptoms:</td>
</tr>
<tr>
<td></td>
<td>&gt; nature and history of any mass</td>
</tr>
<tr>
<td></td>
<td>&gt; details regarding:</td>
</tr>
<tr>
<td></td>
<td>o pain, ulceration, itching and changes in size</td>
</tr>
<tr>
<td></td>
<td>o presence and duration of dental symptoms</td>
</tr>
<tr>
<td></td>
<td>o anorexia</td>
</tr>
<tr>
<td></td>
<td>o weight loss.</td>
</tr>
<tr>
<td></td>
<td>Enquire about associated risk factors, including:</td>
</tr>
<tr>
<td></td>
<td>&gt; smoking (consider chewing tobacco, betel nut, paan, pituri or native chewing tobacco)</td>
</tr>
<tr>
<td></td>
<td>&gt; alcohol consumption</td>
</tr>
<tr>
<td></td>
<td>&gt; diet</td>
</tr>
<tr>
<td></td>
<td>&gt; gastro-oesophageal reflux disease (GORD)</td>
</tr>
<tr>
<td></td>
<td>&gt; familial history of head and neck cancer</td>
</tr>
<tr>
<td></td>
<td>&gt; sexual history</td>
</tr>
<tr>
<td></td>
<td>&gt; exposure to environmental factors especially hardware dust</td>
</tr>
<tr>
<td><strong>Physical examination</strong></td>
<td>Examine patient for:</td>
</tr>
<tr>
<td></td>
<td>&gt; neck or orbital masses</td>
</tr>
<tr>
<td></td>
<td>&gt; ulceration of oral mucosa</td>
</tr>
<tr>
<td></td>
<td>&gt; oral swellings</td>
</tr>
<tr>
<td></td>
<td>&gt; red, or red and white, patches</td>
</tr>
<tr>
<td><strong>Full blood examination (FBE)</strong></td>
<td>Aim for test results to be available to the patient within 1 week</td>
</tr>
<tr>
<td><strong>Serum biochemistry (MBA20)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Coagulation studies</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Chest X-ray</strong></td>
<td>&gt; Many patients at risk of cancer of the upper aerodigestive tract are also at risk of primary synchronous lung tumour, because of shared associated tobacco use</td>
</tr>
<tr>
<td><strong>Ultrasound ± fine needle aspiration (FNA) cytology</strong></td>
<td>&gt; If a neck lump persists or grows (including thyroid, salivary gland or lymph node), ultrasound-guided fine needle aspiration cytology (USgFNAC) provides the most accurate information and assists referral</td>
</tr>
<tr>
<td><strong>CT Scan</strong></td>
<td>&gt; If a mass or swelling is evident in the head or neck, a CT from skull base to mediastinum (or diaphragm pending site and findings) is reasonable</td>
</tr>
</tbody>
</table>
Referral

Table 7.2 details the process for appropriate referral of patients presenting with symptoms of head and neck cancer.

### Table 7.2 Referral to a head and neck specialist for suspected head and neck cancer

<table>
<thead>
<tr>
<th>How</th>
<th>What</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP referral form can be communicated via phone, email or web referral</td>
<td>&gt; The most rapid form of referral technology should be used (e.g. Enterprise Patient Administration System or EPAS)</td>
</tr>
<tr>
<td></td>
<td>&gt; Key contact should be the ENT registrar</td>
</tr>
<tr>
<td></td>
<td>&gt; Phone discussion is strongly recommended to facilitate an urgent appointment</td>
</tr>
<tr>
<td></td>
<td>&gt; Timeframe to see a specialist should be <strong>within 2 weeks of presentation</strong></td>
</tr>
<tr>
<td></td>
<td>&gt; Referral to OTHNS surgeon should be made for investigation of suspected larynx or pharynx cancer</td>
</tr>
<tr>
<td></td>
<td>&gt; Referral to Oral-Maxillo-Facial surgeon should be made for investigation of suspected oral cancer</td>
</tr>
</tbody>
</table>

The **referral letter** to a head and neck specialist should include:

> history of presenting signs (clinical history)
> recordings of current and previous weight
> past medical history, including current medications and allergies
> relevant psychosocial history
> all relevant investigations and imaging
> most appropriate contact details for patient, e.g. mobile phone number or the phone number of a relative or carer if the patient speaks limited or no English

### 7.4. FURTHER INFORMATION

> **Appendix H**: Cancer Resources In South Australia
> **Appendix I**: Referral for Psychosocial Support
> The Sydney Head and Neck Cancer Institute: [www.shnci.org](http://www.shnci.org)
> Resources tailored to the needs of country cancer patients, their families, carers, supporters and health professionals: [http://www.countrycancersupport.com.au](http://www.countrycancersupport.com.au)
RECOMMENDATIONS

➤ All individuals with suspected symptoms of head and neck cancer should be referred to a head and neck cancer specialist within 2 weeks of identification by a GP / dentist.

➤ The process for notification to a GP or Dentist should be initiated within 24 hours of referral to a head and neck cancer specialist if the patient does not arrive.

➤ Early referral should be made to a Head and Neck Cancer care co-ordinator to address concerns while awaiting confirmation of a diagnosis.

➤ Health professionals (GPs, dentists, pharmacists, community nurses and GP practice nurses) should be aware of ‘red-flag’ symptoms, risk factors for head and neck cancer, and surveillance of high-risk groups. All people identified in the ‘urgent referral’ category with symptoms and associated high-risk lifestyle behaviours consistent with head and neck cancer should be triaged for rapid access for investigations.

➤ Further research is needed to identify and address reasons for delayed reporting of symptoms and reluctance to seek medical care by some population groups.

➤ A benchmark of 4 weeks from GP identification of head and neck cancer symptoms to GP referral to a head and neck cancer specialist should be used.

➤ Definitive treatment should start within 62 days of urgent GP referral.
8. DIAGNOSIS AND STAGING

In cases of suspected head and neck cancer it is essential to confirm the diagnosis and establish the histopathological sub-type of the tumour.

Pathological investigations are the basis of accurate cancer staging and stratification of clinical outcomes. Any clinically suspected diagnosis of head and neck cancer should be confirmed by biopsy or cytology before treatment.

8.1. OVERVIEW OF DIAGNOSIS AND STAGING

The goal of histopathological analysis of a biopsy or resected specimen is to make a histological tissue diagnosis and/or obtain histological information that may influence the approach to treatment.

A diagnostic pathologist is required to make a diagnosis that will assist the surgeon and oncologist to provide prognostic information to the patient, and guide the treatment decision.

The diagnostic investigations recommended to obtain the tissue diagnosis will depend on the tumour location, together with fitness and preferences of the patient.

8.2. PATHOLOGICAL INVESTIGATIONS

Table 8.1 provides an overview of the cellular pathological investigations used to inform a diagnosis of head and neck cancer.

Table 8.1 Pathological investigations for the diagnosis of head and neck cancer

<table>
<thead>
<tr>
<th>Investigation</th>
<th>Detail/purpose</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biopsy and histopathological...</td>
<td>&gt; For masses that are potentially amenable for ultrasound/CT guided biopsy</td>
<td>Procedure</td>
</tr>
<tr>
<td>Fine needle aspiration (FNA) cytology</td>
<td>&gt; Recommended as a safe, accurate and efficient method in the diagnosis of neck and salivary gland mass lesions</td>
<td>&gt; FNA can be directed by palpation or guided by ultrasound/CT scan if masses are impalpable or heterogeneous</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&gt; Three to four passes with a 21–25 gauge needle are suggested with the preparation of air-dried and at least one alcohol-fixed smear</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specimen transport</td>
</tr>
<tr>
<td></td>
<td>&gt; Material should be taken into Hanks solution to enable possible cell block creation for routine paraffin processing or a sample for lymphocyte surface marker studies in cases of suspected lymphoma</td>
<td></td>
</tr>
<tr>
<td>Investigation</td>
<td>Detail/purpose</td>
<td>Process</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Fibreoptic endoscopic biopsies    | > For masses that are potentially not accessible via US or CT guided biopsy  
> All patients should have an examination of their aerodigestive tract under general anaesthesia to allow for mapping of tumour extent, assessment of feasibility for resection  
> Biopsies should be conducted with direct vision of the tumour  
> Biopsy should be incisional, as excisional biopsies are oncologically unsafe and can cause difficulty establishing accurate margins of treatment for definitive diagnosis | Procedure  
> The person performing the biopsy (pathologist, radiologist, or surgeon) should have experience in sampling techniques for head and neck tumours  
> A combined approach involving two or all of the above specialists may be desirable in some cases  
Specimen transport  
> Samples taken fresh or in saline should be sent urgently to the appropriate pathology laboratory to minimise tissue autolysis. Placing those samples into containers cooled by ice is advantageous  
> Photography of oriented or complex surgical pathology specimens in the pathology laboratory and availability of a range of permanent ink colours to mark surgical margins is recommended |
| Intraoperative investigation      |                                                                                                                                                                                                           |                                                                                                                                                                                                      |
| Frozen section analysis           | > A diagnosis of cancer will already have been made before the time of surgery.  
> The most common reasons for performing frozen section analysis is to assess the margins of resection to confirm it is clear of residual cancer.  
> Frozen section material is occasionally made available for diagnosis during the operation. Unless the tumour is poorly differentiated, it is usually possible to determine the type of tumour. | Procedure  
The surgeon should:  
> be responsible for selecting the frozen section material; tissue samples must remain limited in size to avoid selection bias on the part of the pathologist  
> submit frozen sections from threatened margins of the resection field  
> indicate the margin on this material  
Analysis  
The pathologist should:  
> process the tissue in a way that an assessment regarding this resection margin can be made  
Consultation between the pathologist and the surgeon is essential if:  
> the orientation of the frozen section is uncertain  
> the pathologist considers the submitted tissue specimen too large for frozen section analysis |
8.3. HISTOPATHOLOGY REPORTING

Synoptic reporting is recommended to standardise content and enhance consistency in pathologic diagnosis and patient management. Pathologists are advised to refer to the following guidelines in the reporting of head and neck cancers:

> Royal College of Pathologists Australasia (RCPA) *Structured reporting protocol for oral cancer* (First edition) 2011


The guidelines describe the minimum data that must be included in the pathology report for resected specimens of head and neck cancer originating in the oral cavity, pharynx, larynx, and nose. This is important, as some aspects of invasive cancer, such as the type, size, and grade of the primary tumour, pattern of invasion, minimum resection margin, lymph node status, and presence of extranodal tumour growth, correlate with the course of the disease.

A copy of all malignant pathology reports should be forwarded to the State Cancer Registry for notification.

Minimum data set

Keeping a database of individual cancer presentations and treatment allows not only for optimised individual care of the patient, but also for comparative audit and reporting of outcomes. A database has been accepted as a statutory requirement for cancer registries.

In order to reduce duplication from public and private head and neck centres, it is recommended that there is standardised and integrated data collection at all head and neck cancer multidisciplinary team (MDT) meetings. Ideally, this should be in line with a national minimum data set.

A generic minimum data set for head and neck cancer is provided in Appendix L. Minimum data sets for specific head and neck cancers are provided in Appendix M. Specific cancers include:

- oral cancer
- larynx cancer
- salivary gland cancer
- nasopharynx cancer
- mucosal melanoma of the head and neck.

8.4. STAGING INVESTIGATIONS

Staging is the cornerstone of treatment planning for head and neck cancers. Head and neck cancer is staged using the revised *International Staging System* published by the International Union against Cancer (IUAC) and the American Joint Committee on Cancer (AJCC) (7th Edition).

There are two parts to this staging system:

> cell type

> anatomical staging (TNM), which provides information about the size of the primary tumour (T), degree of regional nodal involvement (N), and extent of metastases (M).

The AJCC TNM status involves combined clinical (cTNM), radiologic (rTNM) and pathological assessment (pTNM), as complementary staging data are acquired with each different approach (Table 8.2).
Table 8.2 Anatomical staging investigations in head and neck cancers

<table>
<thead>
<tr>
<th>Staging</th>
<th>Investigation/s</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical (cTNM)</td>
<td>&gt; Physical examinations</td>
<td>&gt; Used to identify and evaluate primary lesion</td>
</tr>
<tr>
<td></td>
<td>&gt; Radiological tests</td>
<td>&gt; Includes panendoscopy, which should be carried out by the same team responsible for any future procedures for the patient</td>
</tr>
<tr>
<td>Pathological (pTNM)</td>
<td>&gt; Surgery</td>
<td>&gt; Histopathological examination of resected tissue is useful in selecting patients for post-operative adjuvant therapy, and for estimating prognosis</td>
</tr>
<tr>
<td>Radiological (rTNM)</td>
<td>&gt; Computed tomography (CT)</td>
<td>&gt; Used to help delineate the extent and size of the primary tumour and presence of lymph node involvement and distant metastases</td>
</tr>
<tr>
<td></td>
<td>&gt; Magnetic Resonance Imaging (MRI)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; Positron emission tomography (PET)</td>
<td></td>
</tr>
</tbody>
</table>

8.5. FURTHER INFORMATION

> Appendix N provides further detail on the recommended data inclusions for the pathologic reporting of head and neck carcinomas


RECOMMENDATIONS

> Synoptic reporting should be implemented as the standard for histopathologists evaluating head and neck/salivary gland malignancy.

> Synoptic reporting templates should be reviewed at least every 2 years to ensure prognostic relevant data are included and up to date.

> Collection of defined national minimum dataset on all head and neck cancer patients should be mandated through a national model.

> It is recommended that tissue samples for diagnosis (histology, cytology, molecular markers) are obtained within 1 week of consultation with the specialist to ensure treatment is not delayed for those with a potentially curable cancer.

> Staging investigations (note exceptions) should be done within 1 week of tissue confirmation of head and neck cancer.

> PET-FDG (used with clear guidelines) should be a routine tool for patients with locally advanced disease, where treatment intent is curative.

> Radiology and Pathology departments require referrals for patients to be discussed at the MDT meeting at least 2 days before the meeting to enable collation and photography of slides, and ordering of additional tests if needed. If slides need to be sourced from another local laboratory, 5 working days is recommended. This can be modified for urgent requests.
9. PRESENTATION AT HEAD AND NECK CANCER MULTIDISCIPLINARY TEAM MEETING

Multidisciplinary team (MDT) members meet regularly to provide treatment recommendations, while taking into account the clinical and psychosocial aspects of patient care, individual patient preferences and circumstances.76

9.1. MULTIDISCIPLINARY TEAM MEETINGS

MDT meetings provide the opportunity for:

- discussion of all new patient presentations
- review of patients following surgery, neoadjuvant treatment and tumour recurrence
- discussion of clinical trial access and patient eligibility.

The benefits of multidisciplinary care for patients, families and health professionals are well documented. Further information on multidisciplinary care is provided in Chapter 3 Multidisciplinary and coordinated care, and in Appendix B.

Treatment and supportive care within the MDT should be coordinated, ensuring that the patient, GP and MDT members are clear about individual responsibilities for coordination of care.

Referral to an MDT meeting

The referring specialist to the MDT meeting is responsible for patient care until care is formally referred or passes to another practitioner. Any health professional can refer to the MDT meeting for additional treatment, discussion and management planning should complexities arise along the care continuum.77 The referral process for presentation at an MDT meeting is outlined in Box 9.1.

Box 9.1 Referral for presentation of a patient with head and neck cancer at an MDT meeting

- Patient consent must be obtained (written or verbal) before presentation at the head and neck cancer MDT meeting
- Referring clinician must liaise with MDT meeting Chair or delegate (usually MDT meeting coordinator)
- Referring clinician complete s MDT meeting referral form (specific to each hospital) and ensures submission by the stated date and time. This is usually at least 48 hours prior to the meeting, as the list is finalised by the MDT meeting coordinator 1 day prior
- Referring clinician must ensure radiology is available for the meeting. The MDT meeting co-ordinator may be able to facilitate this when provided with relevant information to source radiology images/pathology (location, day of imaging for private films)
- Routine diagnosis and staging should be complete prior to the MDT meeting
- Access to technology includes; videos, clinical photographs, diagnostic endoscopy/video documentation
Reporting of an MDT meeting

The MDT meeting should be held weekly to allow for timely discussion of patients, avoid delay in management of patients and provide timely feedback to patients.

At the meeting, individual patient data from clinical, medical imaging and pathology sources are reviewed to provide a tissue diagnosis and TNM stage. MDT meeting discussion aims to develop a consensus treatment plan based on clinical characteristics, individual patient preferences and circumstances, tissue diagnosis and TNM stage.

The treatment consensus is recorded by the MDT meeting Chair and is communicated to the referring clinician for discussion with the patient (Box 9.2).

**Box 9.2 Patient MDT meeting summary**

- Referring documentation records should be:
  - kept by the MDT meeting Chair / MDT meeting coordinator / MDT meeting administrative support
  - filed in the patient’s clinical record

- **MDT meeting recommendation** proforma (Oacis or EPAS clinical summary) should include:
  - treatment and management recommendations
  - clearly defined goal of treatment

- Summaries and letters need to be communicated in a timely manner with the patient’s GP and private practitioners who do not have access to EPAS.

- The primary treating specialist (that is, the specialist with whom the patient primarily discusses decision making for their clinical management) should be documented

- The signature of the MDT meeting Chair is required on the MDT meeting recommendation proforma, and these record should be made available to the referring clinician and inserted into the patient clinical record

- The MDT meeting coordinator should retain the Chair’s copy of the agenda in a secure manner for audit purposes
9.2. HEAD AND NECK MULTIDISCIPLINARY TEAM

The head and neck MDT comprises both core members who attend all meetings and associate team members who may attend on referral for treatment for cancers that may need to be managed jointly (e.g. rare tumours of skull base and salivary gland) (Table 9.3).

Table 9.3 Membership of the Head and Neck MDT

<table>
<thead>
<tr>
<th>Core members</th>
<th>Members via referral</th>
</tr>
</thead>
<tbody>
<tr>
<td>OTHNS surgeon</td>
<td>Neurosurgeon</td>
</tr>
<tr>
<td>Plastic and reconstructive surgeon</td>
<td>Upper GI surgeon</td>
</tr>
<tr>
<td>Dentist</td>
<td>Vascular surgeon</td>
</tr>
<tr>
<td>Medical oncologist</td>
<td>Ophthalmologist</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>Psychiatrist</td>
</tr>
<tr>
<td>Pathologist</td>
<td>Pain management specialist</td>
</tr>
<tr>
<td>Nuclear medicine specialist with PET expertise</td>
<td>Addiction services</td>
</tr>
<tr>
<td>Radiologist ± PET-trained imaging specialist</td>
<td>Audiology</td>
</tr>
<tr>
<td>Respiratory physician</td>
<td>Geriatric cancer</td>
</tr>
<tr>
<td>Palliative medicine physician</td>
<td>Assessment team</td>
</tr>
<tr>
<td>Specialist nurse</td>
<td>Adolescent and young adult cancer assessment team</td>
</tr>
<tr>
<td>Allied health according to patient need</td>
<td>CALD and ATSI services; Cancer care coordinator in Aboriginal health</td>
</tr>
<tr>
<td>Clinical trial coordinator</td>
<td>Occupational therapist</td>
</tr>
<tr>
<td>Data manager</td>
<td>Rural/ remote liaison nurse</td>
</tr>
<tr>
<td>MDT meeting coordinator / Pathway project</td>
<td></td>
</tr>
<tr>
<td>officer / Administrative officer</td>
<td></td>
</tr>
</tbody>
</table>

9.3. COMMUNICATION OF MDT MEETING OUTCOMES

Following presentation at the MDT meeting, the referring clinician or delegate is responsible for discussing the meeting recommendations (including rationale, aims, likely beneficial and adverse side effects and other treatment options) with the patient / family / carer within 3 working days.51

The final treatment plan, taking into account the patient’s preferences, should be documented and communicated to the patient, their family and treating clinicians. Details of changes due to patient preferences or further results should be documented in the patient record by the referring clinician and communicated to the GP and other relevant treating clinicians.51

9.4. FURTHER INFORMATION

> Appendix O Head and Neck Cancer Multidisciplinary Team Meeting Terms of Reference


RECOMMENDATIONS

› All patients with a diagnosis of head and neck cancer should be discussed prospectively at an MDT meeting within 14 days of a confirmed diagnosis.

› MDT meetings must be appropriately resourced. This includes administrative support and an MDT meeting coordinator and / or administrative support (administrative A03 level). Administrative processes should be standardised with clear protocols.

› TNM staging of head and neck cancer cases discussed at the MDT meeting should be recorded for all cases.

› A copy of the treatment plan, including any revisions made following patient discussion, should be sent to the referring GP within 3 working days of the MDT meeting. A copy should also be placed in the patient's case file and sent to the specialist responsible until care is formally referred and passed on to another practitioner.

› Where possible, patients should be offered clinical trial enrolment.

› Improvements to telehealth facilities will facilitate initial patient assessment and post-treatment follow-up (where clinically appropriate) with GPs.
10. TREATMENT

Treatment of head and neck cancers requires complex multimodality therapy and surgical expertise from a variety of disciplines. This chapter provides a high-level overview of multimodal therapies employed in the treatment of head and neck cancer.

Treatment for head and neck cancer is determined by tumour type, stage of disease, co-morbidities, performance status and patient choice. A multidisciplinary approach to care is essential to successfully manage care and outcomes.

This section provides a high-level overview of practice guidelines for treatment modalities that are common in the management of different types of head and neck cancers. Further information on these treatment modalities is provided in Appendix P.

Practice guidelines for the treatment of specific head and neck cancer tumour types are detailed in Appendix Q. Specific tumour types addressed in the Appendix Q include:

- oral squamous cell carcinoma
- oropharyngeal squamous cell carcinoma
- hypopharyngeal squamous cell carcinoma
- laryngeal squamous cell carcinoma
- unknown Primary squamous cell carcinoma

Clinical judgment and preferences/clinical situations must be taken into account when planning care.

Respecting patient choice

Where patients have been offered curative treatment and decline this, the reasons for doing so should be documented in the medical record, and all attempts made to convey this to all health professionals involved in the care of the patient (especially GP or Aboriginal health workers). It is important that such patients are not excluded from care, and that they are offered regular attendance at surveillance clinics to review symptoms and offer ongoing supportive care.

The role of clinical trials

The evidence base for head and neck cancers is low, with few randomised controlled trials of treatments. It is still important to offer enrolment for clinical trials, where appropriate.

A number of websites provide information about clinical trials for consumers. The Consumers Health Forum of Australia have published a Consumer Guide to Clinical Trials, which can be accessed at: https://www.chf.org.au/pdfs/chf/CHF-Clinical-trials_COL__WEB.pdf
10.1. OVERVIEW OF TREATMENT MODALITIES FOR HEAD AND NECK CANCER

The major modalities of head and neck cancer treatment are surgery, chemotherapy and radiotherapy. Treatment aims include cure, increasing disease free survival or time to progression, symptom control and palliation.

Further information about the dietetic pathways for people with neck and neck cancer undergoing treatment is provided in Appendix J and Appendix K.

Surgery

Surgical resection of head and neck cancers may involve:

- removal of the **primary tumour**
- removal of **lymph node/s** in cases where there is clinical and/or radiologic evidence for the presence of lymph node metastases (See Table 10.1).

### Table 10.1 Types of surgery for head and neck cancer

<table>
<thead>
<tr>
<th>Surgery</th>
<th>Detail</th>
</tr>
</thead>
</table>
| **Primary tumours** | Resection of primary tumour is performed to:  
> remove the tumour with an adequate margin  
> provide a specimen for accurate histopathologic staging to allow prognostic evaluation and stratification of therapy  
> allow for each patient to have treatment appropriate to their tumour that allows best oncologic control and least functional impairment  
> resect primary tumours previously treated with radiotherapy ± chemotherapy where there remains concern or evidence of persistence of malignancy in the primary site. |
| **Lymph nodes**   | Resection of lymph nodes is performed:  
> to allow stratification of therapy in cases that are clinically and radiologically negative, but have a high index of suspicion for the presence of microscopic nodal metastases  
> in cases previously treated with radiotherapy ± chemotherapy where there remains concern or evidence (clinical, radiologic, cytopathologic) of persistence of metastatic malignancy in treated nodes. |

Surgery is considered as part of the primary treatment for a number of head and neck cancer types when the primary tumour site is accessible, including:

- oral squamous cell carcinoma  
- oropharyngeal squamous cell carcinoma  
- hypopharyngeal squamous cell carcinoma  
- laryngeal squamous cell carcinoma  
- unknown Primary squamous cell carcinoma.

Further detail about the decision making process and treatment management for these tumour types is provided in Appendix Q.
Plastic and reconstructive surgery

Reconstructive surgery following upper aerodigestive tract tumour excision may be required to:

- restore function of chewing, speech and swallowing
- support the eye globe (sinus excision)
- seal off the aerodigestive tract or dura from the surrounding soft tissues of the neck
- restore functional animation to the face
- offer a favourable aesthetic outcome.

Options for reconstructive surgery depend on the site of the tumour, size of defect and prognosis for restoration of function. Options may involve reconstruction via a local tissue flap or the use of tissue from a distant site.

Chemotherapy

There are four times during treatment when chemotherapy may be considered for patients with head and neck cancer (Table 10.2). The choice and timing of chemotherapy will be dependent on several factors, including stage of disease, potential operability, patient preference and existence of comorbidities.

Chemotherapy is not indicated in early-stage head and neck cancer where the 5-year overall survival is 80–90% (for stage I disease) and 65–80% (for stage II disease).

Table 10.2 Chemotherapy for head and neck cancer

<table>
<thead>
<tr>
<th>Chemotherapy</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitive chemoradiotherapy</td>
<td>&gt; Chemotherapy combined with radiotherapy</td>
</tr>
<tr>
<td></td>
<td>&gt; Used with <strong>curative intent</strong> in patients with locoregionally advanced head and neck cancer who are deemed medically unfit for surgery, or where surgery is deemed unnecessarily morbid, or where the patient declines surgery</td>
</tr>
<tr>
<td>Induction (or neoadjuvant)</td>
<td>&gt; Used with <strong>curative intent</strong>, prior to definitive surgery or chemoradiotherapy.</td>
</tr>
<tr>
<td></td>
<td>&gt; Aims to downsize the tumour prior to definitive treatment</td>
</tr>
<tr>
<td></td>
<td>&gt; Has been shown to reduce the rate of distant metastases</td>
</tr>
<tr>
<td>Postoperative</td>
<td>&gt; Given post-operatively for the management of high-risk patients</td>
</tr>
<tr>
<td></td>
<td>&gt; Used with curative intent</td>
</tr>
<tr>
<td>Palliative</td>
<td>&gt; Given for recurrent or metastatic disease, or very advanced locoregional disease</td>
</tr>
<tr>
<td></td>
<td>&gt; Used when there is no possibility of surgical resection of the locoregional disease and curative radiotherapy options have been exhausted</td>
</tr>
</tbody>
</table>

Further information about the role of each type of chemotherapy listed above, as well as associated toxicities, is provided in **Appendix P**.
Radiotherapy

Treatment of head and neck cancer with radiotherapy is complex (Table 10.3). The decision to treat with radiotherapy is dependent on anatomical site, tumour stage, neck node size, and multiple patient factors, including co-morbidities, performance status and patient preference. 

Radiotherapy can be delivered for curative intent as primary treatment in the setting of organ conservation, as an adjuvant to surgery (pre-operatively or post-operatively for patients at high risk of locoregional recurrence), or in combination with chemotherapy.

Table 10.3 Radiotherapy for head and neck cancer

<table>
<thead>
<tr>
<th>Radiotherapy</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary treatment</td>
<td>&gt; Used with curative intent as major first-line treatment modality</td>
</tr>
<tr>
<td></td>
<td>&gt; Types of first-line radiotherapy include:</td>
</tr>
<tr>
<td></td>
<td>o conventional fractionation</td>
</tr>
<tr>
<td></td>
<td>o altered radiation fractionation</td>
</tr>
<tr>
<td></td>
<td>o intensity-modulated radiation therapy (IMRT).</td>
</tr>
<tr>
<td>Adjuvant treatment</td>
<td>&gt; Used pre-operatively to downsize the tumour prior to surgery</td>
</tr>
</tbody>
</table>
|                  | > Used post-operatively for patients at high risk of locoregional recurrence; the total treatment time calculated from the start of surgery to the end of radiotherapy should be kept as short as possible. 
|                  | > Used in combination with chemotherapy; concomitant chemoradiotherapy (CCRT) is considered the established standard for non-surgical management of locally advanced (stage 3 and 4) head and neck cancers |
|                  | > For patients with head and neck cancer with positive resection margins (<1 mm) and/or extranodal growth, post-operative chemoradiation is significantly more effective than post-operative radiotherapy (8–12% improvement in locoregional control and disease-free survival) |
| Palliative radiotherapy | > Used symptom management, such as bone pain associated with metastases |

Further information about the role of each type of radiotherapy listed above, as well as associated toxicities, is provided in Appendix P.
10.2. SPECIAL NEEDS DENTISTRY FOR HEAD AND NECK CANCER

Surgery and radiotherapy for head and neck cancer can induce oral side effects requiring specialist dentist intervention. Common oral side effects of surgery and radiotherapy are outlined below.

Oral side effects of head and neck cancer surgery

The oral side effects of oral and oropharyngeal cancer surgery may include impairment of:

- salivary control, resulting in drooling due to altered lip competence and tongue mobility
- masticatory ability, impacting on nutrition and diet
- temporomandibular joint function, with trismus and mandibular deviation
- swallowing function
- speech.

Oral side effects of head and neck radiotherapy

During and after radiotherapy, some degree of transient and/or permanent damage will occur to the oral tissues resulting in oral complications ranging from mild post-treatment damage, to life threatening necrosis. The consequences of head and neck radiotherapy are presented in Figure 10.1.

Figure 10.1 Direct and Indirect consequences of head and neck radiotherapy.
The oral side effects of head and neck radiotherapy are presented in Table 10.4.

Table 10.4 Oral side effects of head and neck radiotherapy

<table>
<thead>
<tr>
<th>Affected area</th>
<th>Side effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral mucosa</td>
<td>&gt; Mucositis</td>
</tr>
<tr>
<td></td>
<td>&gt; Taste loss/dysguesia</td>
</tr>
<tr>
<td>Salivary glands</td>
<td>&gt; Hyposalivation/xerostomia</td>
</tr>
<tr>
<td>Dentition and periodontium</td>
<td>&gt; Alteration to the oral microflora</td>
</tr>
<tr>
<td></td>
<td>&gt; Increased caries risk</td>
</tr>
<tr>
<td></td>
<td>&gt; Increased risk of periodontal disease</td>
</tr>
<tr>
<td>Musculature</td>
<td>&gt; Glossitis</td>
</tr>
<tr>
<td></td>
<td>&gt; Dysphagia</td>
</tr>
<tr>
<td></td>
<td>&gt; Muscle fibrosis</td>
</tr>
<tr>
<td></td>
<td>&gt; Trismus</td>
</tr>
<tr>
<td>Bone</td>
<td>&gt; Osteoradionecrosis (ORN)</td>
</tr>
</tbody>
</table>

Oral complications following head and neck radiotherapy are dose dependant, and can have a significant impact on a patient’s quality of life. Clinical side-effects can be acute / short-term to intermediate, to chronic / long-term (Figure 10.2).

Figure 10.2 Schematic diagram of time, onset and duration of radiation induced oral sequelae.
Role of the special needs dentist

Management of oral side effects of head and neck cancer treatments requires the **involvement of a special needs dentist during the planning, treatment and follow-up of patients** (Table 10.5). Radiation-induced late oral side-effects can often be reduced to some degree with appropriate prevention and/or treatment.

**Table 10.5 Involvement of a special needs dentist in the care of patients with head and neck cancer**

<table>
<thead>
<tr>
<th>Treatment stage</th>
<th>Role of the special needs dentist</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-treatment</strong></td>
<td>➢ As part of the MDT, the special needs dentist will develop a dental treatment plan in line with the oncology treatment plan  &lt;br&gt; ➢ Post-treatment prosthetic requirements need to be considered for patients who require either a hemi-maxillectomy or hemi-mandibulectomy  &lt;br&gt; ➢ Patients requiring hemi-maxillectomy who are not to be immediately reconstructed will require an obturator to be constructed prior to surgery  &lt;br&gt; ➢ The special needs dentist will need to be available at time of surgery to ‘fit’ the obturator  &lt;br&gt; ➢ Any teeth in the radiation field with poor prognosis need to be extracted at time of surgery or a minimum of 10–14 days prior to the commencement of radiotherapy to reduce the risk of osteoradionecrosis  &lt;br&gt; ➢ Patients also need to be provided with appropriate oral health advice</td>
</tr>
<tr>
<td><strong>Peri-treatment</strong></td>
<td>➢ Surgical site and oral hygiene management should be reviewed approximately 2 weeks post-surgery  &lt;br&gt; ➢ If a surgical obturator has been placed, the prosthesis needs to be removed and modified as required; the patient will also require instruction on how to place and remove the prosthesis, as well as advice on how to care for the prosthesis  &lt;br&gt; ➢ During radiotherapy, the patient needs to be reviewed on a weekly basis to assess and manage effects of radiation damage to the oral tissues</td>
</tr>
<tr>
<td><strong>Post-treatment</strong></td>
<td>➢ Patient should be reviewed 6–8 weeks following the completion of radiotherapy to assess the resolution of mucositis, and so that oral hygiene and preventive care protocols can be commenced</td>
</tr>
<tr>
<td><strong>Follow-up</strong></td>
<td>➢ Patients who undergo head and neck radiotherapy should be reviewed at least 6-monthly during the first 2 years post-radiation to monitor their oral health  &lt;br&gt; ➢ Surgical obturators should be replaced with a definitive prosthesis preferably no longer than 6 months post-surgery</td>
</tr>
</tbody>
</table>
Management of oral side effects

Protocols for the management of oral side effects are based on clinical experience and anecdotal evidence only, with very few evidence-based clinical practice guidelines available. As a result, there is great diversity in supportive care policies and preventive approaches. Table 10.6 outlines the suggested approaches to treatment of common oral side effects.

Table 10.6 Treatment of oral side effects

<table>
<thead>
<tr>
<th>Side effect</th>
<th>Treatment</th>
</tr>
</thead>
</table>
| Mucositis     | ▶ Management options can include:  
  - removal of mucosal irritating factors  
  - cleansing of the oral mucosa  
  - maintenance of mouth and lip moisture  
  - relief of mucosal pain and inflammation through use of mucosal coating agents, topical anaesthetics or systemic analgesics.  
  - prevention and treatment of oral infection(s) especially fungal  
  - discouraging smoking or alcohol consumption  
  - limitation of ingestion of spicy or acidic foods  
  - Oral bactericidal or bacteriostatic chemotherapeutic agents applied topically are recommended for maintenance of oral hygiene during radiotherapy  
  - MASCC/ISOO Mucositis guidelines (2005) recommend that chlorhexidine should not be used to prevent oral mucositis in patients with solid tumours of the head and neck who are undergoing radiotherapy  
  - Benzydamine hydrochloride (‘Difflam’) is the only oral chemotherapeutic agent available which has been shown in multi-centre double blind trials to reduce oral mucositis and pain in patients with head and neck cancer  |
| Hyposalivation| ▶ Management options can include:  
  - stimulation of any residual secretory capacity of the affected salivary gland(s) through the use of gustatory, masticatory or pharmacologic sialagogues  
  - use of saliva substitutes (artificial saliva) and/or the use of preventive regimes to limit potential damage to the dentition and mucosa as a result of the altered salivary flow and composition  
  - Saliva substitutes based on carboxymethylcellulose or mucin are available; mucin-based saliva substitutes are the most commonly preferred by patients  
  - Saliva replacements are usually a poor substitute in the long-term  
  - The simplest and most common solution is frequent moistening of the mouth with water; the main disadvantage of this is the necessity for frequent application due to water’s poor retention properties  
  - Severe hyposalivation:  
    - saliva substitutes with gel-like properties (mucin-based)  
  - Moderate hyposalivation:  
    - gustatory and/or pharmacologic stimulation (e.g. Pilocarpine) of residual salivary secretion; if this does not work then use of saliva substitute is
<table>
<thead>
<tr>
<th>Side effect</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Radiation caries</strong></td>
</tr>
<tr>
<td></td>
<td> It is possible to reduce the risk of radiation caries if patients comply with daily application of 1% neutral fluoride, maintain meticulous oral hygiene, reduce intake of cariogenic foods, and use remineralisation products (e.g. toothmousse)</td>
</tr>
<tr>
<td></td>
<td> Radiation caries is a lifelong risk to patients, and as such a lifelong commitment is required by the patient to maintain the preventive regime</td>
</tr>
<tr>
<td></td>
<td><strong>Trismus</strong></td>
</tr>
<tr>
<td></td>
<td> Patients should be educated on the application of mobilisation exercises to maintain maximum oral opening and jaw mobility; exercises should commence as soon as possible as a preventive method</td>
</tr>
<tr>
<td></td>
<td> If trismus develops:</td>
</tr>
<tr>
<td></td>
<td>o the exercise program is intensified and, if necessary, combined with physiotherapy to regain lost inter-arch distance</td>
</tr>
<tr>
<td></td>
<td>o the use of dynamic bite opener appliances, such as the Therabite® [Atos, Medical AB, Sweden], may improve trismus through repetitive passive stretching of affected masticatory muscles</td>
</tr>
<tr>
<td></td>
<td> Established trismus that does not respond to exercise can be treated surgically; this must be followed by immediate and prolonged muscle exercise in the post-operative period</td>
</tr>
<tr>
<td></td>
<td><strong>Osteoradionecrosis (ORN)</strong> Pre-treatment dental assessment is critical, with consideration given to:</td>
</tr>
<tr>
<td></td>
<td> pre-radiotherapy dental status</td>
</tr>
<tr>
<td></td>
<td> radiotherapy treatment plan</td>
</tr>
<tr>
<td></td>
<td> prudent management of extraction(s) to</td>
</tr>
<tr>
<td></td>
<td>o ensure an atraumatic procedure is provided, with careful tissue handling and primary closure</td>
</tr>
<tr>
<td></td>
<td>o allow sufficient healing time prior to the commencement of radiotherapy (minimum of 10–14 days and preferably 21 days)</td>
</tr>
</tbody>
</table>

10.3. FURTHER INFORMATION

- **Chapter 5**: Supportive care needs of patients with Head and Neck Cancer
- **Chapter 11**: Complementary therapies
- **Appendix J**: Head and neck cancer dietetic pathway
- **Appendix K**: Head and neck cancer dietetic pathway radiotherapy and/or chemotherapy
- **Appendix P**: Practice guidelines for common treatment modalities
- **Appendix Q**: Practice guidelines for treatment of specific head and neck tumour types
RECOMMENDATIONS

> Surgical treatment of head and neck cancers should be carried out by appropriately trained and credentialed surgeons who maintain a full patient audit and clinical database available for peer review. Peer review should occur at regular defined intervals.

> Head and neck cancer treatments should be provided within an accredited institution with access to supporting facilities as indicated by the level and intensity of therapy required.

> A plastic surgeon should be present at the MDT meeting for identification of patients who may benefit from reconstruction and to advise the MDT of suitable options.

> Patients who are candidates for reconstructive surgery should be assessed in person by the plastic surgeon, alongside the excisional surgeon, to formulate an agreed plan and approach. The plastic surgeon can then assess the patient’s suitability for reconstruction and advise them of the options.

> Following surgery, inpatient progress with reference to reconstruction should be monitored by the plastic surgical team until discharge to ensure optimal care for a successful recovery and return to function.

> Following discharge, all reconstructed patients should be assessed by the plastic surgical team as an outpatient with particular reference to outcome and function of the reconstruction; this follow-up assessment should be in addition to follow-up care for the purpose of cancer surveillance.

> Chemotherapy should be given according to established evidence-based protocols and practices that are standardised across SA.

> Medical oncologists providing chemotherapy for patients with head and neck cancer should be accredited by the RACP and credentialled by their institution for practice in this area.

> Chemotherapy with curative intent may be considered in the following situations using a cisplatin-based therapy:

   a) induction chemotherapy for advanced stage hypopharynx SCC
   b) induction chemotherapy for tumours, other than hypopharynx, when a tumour is sufficiently advanced as to require prompt treatment whilst awaiting definitive surgery or chemoradiotherapy and the patient is considered fit enough to tolerate treatment
   c) definitive chemoradiotherapy where the patient has one of the following: unresectable disease, requires organ preservation, is deemed medically unfit for surgery or declines surgery
   d) post-operative chemoradiotherapy should be considered for patients with poor prognostic features, i.e. positive surgical margins, extracapsular nodal spread of cancer; other high-risk factors with lesser evidence may be taken into consideration, such as perineural/vascular invasion, large number of nodes, and should be decided on an individual basis after discussion in the MDT meeting

> For patients considered for curative chemoradiotherapy in whom cisplatin is contraindicated, the option of cetuximab with radiotherapy should be considered.

> Patients receiving combined modality chemoradiotherapy (or cetuximab) with curative intent should be counselled as to the increased toxicity of combined treatment compared with radiotherapy alone.

> Patients receiving systemic treatment should be seen by a medical oncologist before each dose of chemotherapy and, in the case of cetuximab, at least fortnightly. Blood tests should be conducted before administration of each new dose of systemic treatment and should include a full blood picture, biochemistry, magnesium and potassium, with treatment adjusted accordingly.

> Where the patient is considered to have incurable disease, the patient should be assessed by a
medical oncologist as to their suitability for palliative chemotherapy. This generally requires an ECOG performance status of 0–2. Palliative chemotherapies currently funded in Australia have minimal impact on survival but may enhance quality of life. 

> Radiation oncologists (FRANZCR or equivalent) and departments providing radiotherapy for patients with head and neck cancer should proceed according to established protocols and practice standards outlined for the prescription and delivery of radiotherapy.

> The time from decision to treat to the actual start of treatment should not exceed 4 weeks.

> The time from surgery to post-operative radiotherapy should be approximately 42 days.

> Special needs dentists, preferably with knowledge and experience of oral implantology, should be a core member of the head and neck MDT.

> Referral to a special needs dentist should preferably be made at the time of diagnosis to assist with treatment planning.

> Preventative oral care must be delivered to all patients during and after treatment for head and neck cancer.

> At the end of treatment, a summary of therapy and recommendations for follow-up should be provided to the patient and sent to patient’s personal community dentist.
11. COMPLEMENTARY THERAPIES

Many people with a cancer diagnosis use complementary therapies as an adjunct to conventional cancer treatment, usually to assist in the management of symptoms and side-effects of treatment and to improve quality of life.

The South Australian Cancer Clinical Network recommends health professionals take guidance from the available national principles, and refer patients to reputable resources such as the Cancer Council Helpline for further information.

Complementary and alternative therapies are a diverse group of practices and products not considered part of evidence based, conventional medicine. The term Complementary and Alternative Medicine (CAM) is frequently used to describe this group of therapies; however it is important to distinguish between complementary and alternative therapies.

- Complementary therapies may be used together with conventional medicine.
- Alternative therapies are used instead of conventional medicine.

There is no evidence to support the use of alternative therapies in the treatment of cancer. This Chapter of the cancer pathway provides recommendations for health professionals on the use of complementary therapies as an adjunct to conventional cancer treatments.

11.1. THE USE OF COMPLEMENTARY THERAPIES

In Australia, the use of complementary therapies by people with cancer is rapidly increasing. Their use can be of concern to health professionals who are uncertain of evidence for their benefit. This concern is coupled with confusion over professional standards for CAM providers, availability and access to complementary medicines, different varieties of medicines available and the associated costs.

The South Australian Cancer Clinical Network has endorsed the Clinical Oncological Society of Australia (COSA) position statement ‘The use of complementary and alternative medicine by cancer patients’.

The comprehensive statement provides guidance on the use of CAM for health professionals involved in the management of patients with cancer, including key principles of care (See Box 11.1), discussing CAM, evidence, risks/benefits, harm reduction and reporting adverse events.

**Box 11.1 Key principles for the use of complementary medicine***

- Patient-centred care
- Shared decision-making
- Respect for the patient’s right to make their own decisions about their healthcare
- Effective communication through the provision of a supportive environment that encourages patients to communicate how they are managing their health, including the use of any CAM
- Avoiding prejudice
- Application of risk minimisation principles when a patient chooses to use CAM
- Obligation:
  - providing care to a patient choosing to use CAM does not mean the health professional condones the patient’s decision
  - health professionals are not obliged to provide treatments against their medical judgement when providing care for a patient who chooses to use CAM.
11.2. DISCUSSING COMPLEMENTARY THERAPIES WITH PATIENTS AND/OR CAREGIVERS

Health professional should actively ask patients about their use of CAM to avoid interactions with conventional treatments. When asking a patient about CAM, it is important to remember that many patients may refer to complementary therapies as traditional or natural therapies, herbal supplements, bush medicines or Chinese traditional medicine.

Discussing the evidence

> Health professionals discuss the process of developing evidence for medicines and the value of evidence based clinical studies compared with other sources of information. Health professionals should encourage patients to consider the evidence supporting the use of their chosen CAM.89

> Referral of a patient to another health professional with CAM expertise may be appropriate.89

Discussing implications

> Health professionals should encourage open communication with their patients regarding use of CAM in order to anticipate the potential of drug interactions.89

> Health professionals should discuss the possibility of CAM treatment failure in a similar way as they would discuss possible failure of conventional medicine.89

Keeping a record

> Health professionals should document all discussions they have with their patients about CAM including any advice, type of CAM, CAM provider, patient’s reasons for taking CAM and perceived benefits.89

Reporting harmful CAM and CAM providers

> Some complementary therapists, such as Chinese medicine practitioners, are regulated by national legislation and registers. This can make choosing a practitioner safer.89

> Where there are concerns of CAM services/products or practitioners the SA Health and Community Services Complaints Commissioner may be contacted.

11.3. FURTHER INFORMATION

> Cancer Council, Understanding Complementary Therapies- A guide for people with cancer, their families and friends available online or by phoning the Cancer HelpLine 131120.


> Memorial Sloan Kettering Cancer Center (US), ‘About Herbs, Botanicals and Other Products’: www.mskcc.org/mskcc/html/11570.cfm

RECOMMENDATIONS

> The guiding principles should provide the framework for all complementary and alternative therapies discussions with patients and their carers.

> All patients with cancer should be specifically asked about their use of CAM.

> Discussions and patient and family responses to questions about CAM use should be recorded in the clinical record.
12. FOLLOW-UP CARE

Follow-up care after diagnosis and treatment of head and neck cancer is intended to enable early detection of local, regional or metastatic recurrence, facilitate the management of side effects and complications of treatment, and allow for on-going monitoring of physical and psychosocial supportive needs.

The approach to follow-up care required will vary according to the intent of the initial treatment. All members of the MDT have a role in planning and providing ongoing follow-up care. A follow-up plan is recommended to streamline follow-up and avoid duplication of care by multiple specialists.

12.1. POST-TREATMENT FOLLOW-UP

There is currently no high-level evidence on which to base advice about medical follow-up after completion of treatment for head and neck cancer.

Follow-up appointments should involve:

- a comprehensive history
- physical examination
- radiological, nutrition and speech pathology assessment at intervals of 3–4 months for 2 years.

A suggested follow-up schedule for head and neck cancer patients is presented in Table 12.1.

Table 12.1 Suggested follow-up schedule for people following treatment for head and neck cancer

<table>
<thead>
<tr>
<th>Time since treatment</th>
<th>Frequency of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Surgically treated patients</strong></td>
<td></td>
</tr>
<tr>
<td>Up to 1 year</td>
<td>Every 6–8 weeks</td>
</tr>
<tr>
<td>1–2 years</td>
<td>Every 2–4 months</td>
</tr>
<tr>
<td>2–5 years</td>
<td>Every 6 months</td>
</tr>
<tr>
<td>&gt; 5 years</td>
<td>Individual review by clinician</td>
</tr>
<tr>
<td><strong>Radiotherapy-treated patients</strong></td>
<td></td>
</tr>
<tr>
<td>Up to 2 years</td>
<td>3-monthly (with dental review 6-monthly during the first 2 years)</td>
</tr>
<tr>
<td>2–3 years</td>
<td>4-monthly</td>
</tr>
<tr>
<td>3–5 years</td>
<td>Every 6 months</td>
</tr>
<tr>
<td>&gt; 5 years</td>
<td>Lifelong dental follow-up and rehabilitation</td>
</tr>
</tbody>
</table>

Long-term follow-up after 5 years is to be undertaken in collaboration with the patient and GP for selected patients. All patients treated for head and neck cancer require systematic, coordinated follow-up, as outlined in Table 12.2.
### Table 12.2 Approach to follow-up care for patients who have received curative intent therapy for head and neck cancer

<table>
<thead>
<tr>
<th>Cancer surveillance technique</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case history</strong></td>
<td>&gt; Comprehensive history, physical assessment, annual chest X-ray, rigid or fibreoptic nasopharyngolaryngoscopy, every 6 months for 2 years by the specialist responsible for curative intent therapy</td>
</tr>
</tbody>
</table>
| **Imaging and investigations** | > Post-treatment serial imaging with CT, and/or PET-CT at 4 months post-treatment  
> Negative scanning at 6 months and then at 1 year  
> MRI and PET-CT to be used when recurrence is suspected, especially for the neck and nasopharynx  
> Second-look microlaryngoscopies for laryngeal cancer yearly for 5 years by the specialist physician who diagnosed the primary malignancy  
> Thyroid-stimulating hormone (TSH) levels every 6–12 months if neck has been irradiated  
> Consider Epstein-Barr Virus (EBV) monitoring for cancers of the nasopharynx |
| **Supportive care**         | > Quality of life measures used and compared to baseline data to view changes in physical, emotional, psychological and general health status  
> Dental follow-up recommended for cancers of the oral cavity, oropharynx, hypopharynx and nasopharynx, and for cancers that have received treatment with intraoral radiation  
> Patients offered support with tobacco and alcohol cessation services with pharmaco-therapeutics and counselling offered as needed  
> Patients educated on symptom recognition and detection of recurrence.  
> Ongoing nutritional counselling and support  
> Ongoing speech pathology support for communication, speech, voice and swallow  
> Rural patients to have the option of shared follow-up care between the treating specialist and a local or visiting specialist  
> Immunisation schedules such as annual flu vaccinations  
> Maintaining open lines of communication with patient and family |
13. CANCER RECURRENCE

New symptoms that are indicative of local, regional or distant head and neck cancer recurrence should prompt rapid access to review, and proceed as per the SA Head and Neck Cancer Pathway. All patients with recurrence require a referral to the MDT meeting for discussion.

Locoregional recurrence will occur in approximately 25–50% of patients with advanced stage head and neck cancers. Most patients diagnose their own recurrences (85% are detected by patient and 15% by a health professional).

The gold standard for identifying recurrent or residual disease is histological confirmation, clinical and radiological staging.

13.1. MANAGEMENT OF RECURRENT DISEASE

**Clinical care**

- Investigations may involve:
  - FDG PET-CT for oral cavity and oropharynx, larynx, hypopharynx, nasopharynx, skull base and neck
  - Direct laryngoscopy under general anaesthesia with biopsies following imaging for larynx and hypopharynx
- All patients should be referred to the MDT
- GP and palliative care participation is essential
- Either the referring specialist or a nominated specialist has responsibility for managing treatment of recurrence
- Treatment choice will depend on likely efficacy, morbidity and side effects, patient health and wishes, location and extent of recurrence, and previous management
- Treatment may include:
  - Radiotherapy for localised recurrence
  - Surgery (if a recurrent cancer is confined to one site)
  - Surgery (in patients with a resectable recurrence of oral cavity, oropharyngeal, and laryngeal, hypopharyngeal cancer following previous radiotherapy or surgery)
  - Chemotherapy (for systemic disease)
  - Palliative chemotherapy
  - No treatment (patient choice)

**Supportive care**

- Recurrence can be extremely challenging, confronting and met with more pessimism than the original diagnosis
- Recurrences are also seen in patients with poor general factors, such as inadequate nutrition, alcohol and tobacco abuse
- Active involvement by the Head and Neck Cancer care co-ordinator to support overall care of patient and family
- Patients and their family/carers should be fully informed and counselled about the likely outcome of surgical and radiotherapeutic salvage, with respect to survival, risk of treatment-related morbidity and mortality, and quality of life
- Best supportive care with the aim of maximum symptom palliation
13.2. FURTHER INFORMATION

> Chapter 10: Treatment
> Chapter 14: Palliative care

RECOMMENDATIONS

> A clear documented surveillance plan should be completed with an identified specialist for all patients following completion of treatment for head and neck cancer. The surveillance plan should be provided to the patient and their GP.

> All patients with recurrent head and neck cancers should be referred to the head and neck MDT meeting for discussion and consideration of interventions, including chemotherapy and/or radiotherapy, and to review the plan for ongoing best supportive care.
14. PALLIATIVE CARE

Palliative care aims to improve the quality of life of patients and their families facing life-threatening illnesses, through the prevention and management of symptoms and pain.

A patient-centred palliative approach should be embedded in all cancer care.

14.1. PALLIATIVE INTERVENTIONS AND CARE

The World Health Organisation defines palliative care to be ‘an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.  

The European Society of Medical Oncology (ESMO) defines palliative care as ‘care that aims to optimise the comfort, function and social support of the patient and family when cure is not possible’.

A palliative approach should be embedded in all cancer care. Care should be patient-centred and focused on symptom control at all stages of the disease. A palliative approach ‘encourages a focus on pain and symptom management, and prompts more open communication about end-of-life issues’.

Provision of palliative care

All professionals caring for cancer patients should assess palliative and supportive care needs in initial treatment planning and throughout the illness.

Specialist palliative care teams work in consultation with a patient’s primary health providers to arrange:

- provision of relief from symptoms and symptom control
- physical, social, psychological and spiritual support for patients and their carers when these needs cannot be met by primary care teams.

Specialist palliative care teams work across a range of health care services, from the acute setting to hospice or in the community.

Specialist palliative care teams will have varying involvement in patient care, depending on the stage of a patient’s disease. As the patient nears end of life, the specialist palliative care team may become the primary specialist service involved in patient care, working alongside a GP and other primary care providers. The transition to care primarily led by the specialist palliative care team is best done in a coordinated fashion between the specialist groups, so that the patient understands the reason for transition, how it will occur and ensures the patient, and their family/carers continues to feel well supported.
Referral to specialist palliative care services

A person is eligible for referral to specialist palliative care services if:

> they have progressive, life limiting illness
> they, or their decision maker, is aware of, understands and has agreed to a palliative care referral
> the primary goals of patient care are to control symptoms, maximise function, maintain quality of life and provide comfort.

If a patient does not meet the three eligibility criteria outlined above, the referrer should contact the palliative care service to discuss the referral with a member of the specialist palliative care team.

Referral to a specialist palliative care service can be initiated by health care professionals, patients, carers or family members when:

> the patient requires a palliative care assessment and provision of service information
> symptoms and/or concerns exceed the capacity, resources, knowledge or skills of the primary care provider
> there is difficulty maintaining care at place of residence
> the patient requires terminal care (patient is in the last few weeks of life).

14.2. ADVANCE CARE PLANNING

Advance care planning enables an individual to express their wishes about his or her future health care. Advance directives are based on values of respect, dignity and autonomy. Conversations about the focus of care and the treatment options available should be held early in the course of disease while the patients have the ability to be involved.

Information contained within a patient’s advanced care plan will need to be provided to all health professionals involved in their care including the specialist palliative care team. If a patient does not have a plan in place, the palliative care team can provide support in establishing one with the patient and/or their decision maker. Further information can be found in Chapter 4.

14.3. END OF LIFE CARE

As the end of life approaches, all efforts are made to allow patients to spend their remaining time in the place of their choice, whether this is in their home, hospital or inpatient hospice unit. Health professionals should be mindful of the possibility that this preference may change close to the end of life.

Quality of life in people with advanced cancer is affected by symptoms, loss of function and curtailment of activity, physical effects of treatment, and psychosocial needs. Patients with metastatic disease have a significantly greater unmet need for assistance with physical aspects of daily living compared with the needs of patients without evidence of active disease.

The physical burden faced by patients at the end of life can have a major effect on their emotional wellbeing, and emotional wellbeing of their family/carers. This may be exacerbated by existential and spiritual issues arising from facing death.

Distress can arise as patients and carers are confronted with their own mortality. Existential concerns are reported to be at least as important as the physical, psychological and social supportive care needs of patients and their family/carers in determining quality of life.
14.4. FURTHER INFORMATION

> Palliative Care Australia: www.palliativecare.org.au
> Palliative Care Council of South Australia: www.pallcare.asn.au
> Caresearch: www.caresearch.com.au
> Respecting Patient Choices, Advanced Care Planning www.respectingpatientchoices.org.au/
> National Comprehensive Cancer Network, Clinical Practice Guidelines in Oncology- Palliative Care: http://www.nccn.org

KEY RECOMMENDATIONS

> A palliative approach should be a core principle of care for all treating clinicians.
> A referral to specialist palliative care should be made early in the course of disease for people with complex and unmet needs.
> All patients and their families and/or caregiver should have access to specialist palliative care services if required.
> All patients and their families and/or caregivers would benefit from having a clinician who provides case coordination to ensure that they can navigate the health system.
> All patients and their families and/or care giver(s) require information regarding bereavement support services, while some will require specific assessment and support.
15. SURVIVORSHIP

The USA National Cancer Institute describes survivorship in cancer as covering the ‘physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience.’

15.1. OVERVIEW OF SURVIVORSHIP

Survivors face many issues affecting quality of life, including socioeconomic, psychological, functional and family domains. As many of these domains are integrated, a problem in one area may affect other domains. For example, a survivor may experience a decline in their functional status, restricting family and work related responsibilities, in turn affecting their socioeconomic status and psychological wellbeing.

Figure 15.1 Aspects of survivorship

- **Psychosocial**
  - Integrating back into the community
  - School/employment
  - Change in roles/relationships
  - Loss of hospital support ‘in limbo’

- **Life long surveillance**
  - Late effects, such as secondary malignancy, hyperthyroidism, cardiovascular effects

- **Survivorship**
  - Specialised clinics to coordinate care
  - Counselling, social worker and support groups
  - General practitioner
  - Use of distress tools and appropriate referrals

- **Health promotion**
  - Smoking
  - Alcohol use
  - Weight control
  - Diet/nutrition
  - Exercise
  - Suncare

- **Fear of relapse**
  - Changes in perception of life expectations
  - Changes in priorities

- **Information needs**
  - To have the best chance of survival, the patient and caregivers need information, support and education

- **Medical issues**
  - Depression
  - Fatigue
  - Fertility
  - Cognitive impairment
  - Chronic illness
  - Body image

- **Fear of relapse**
  - Changes in perception of life expectations
  - Changes in priorities
15.2. SURVIVORSHIP AND PATIENT NEEDS

An increase in the number of people surviving cancer has led to an increase in the number of people requiring cancer follow-up care.99

It has become apparent that follow-up services are not meeting the needs of patients. In particular, traditional routine medical follow-up frequently fails to meet the supportive care needs of people following completion of treatment for cancer, often resulting in feelings of abandonment during the transition from cancer ‘patient’ to cancer ‘survivor’.99

Survivorship support plans

It is important to ensure that survivor’s needs are identified and plans made to meet them from an early stage. The benefits of a survivorship support plan are detailed in Box 15.1 below.

Box 15.1: Benefits of a survivorship support plan

- A vehicle for communication between treating physicians and local health providers.
- Help specialists and primary care physicians address questions that patients raise, perhaps years after treatment.
- Allows the patient to make informed health choices and promote healthy lifestyles in an attempt to reduce other co morbid conditions.
- Allows the patient to take some responsibility for their care. It may also ensure adherence to follow-up recommendations.
- Can support and facilitate moving the focus of care back to the community.
- Early detection of health complications that can be ameliorated

Due to the complexity of survivorship needs, it is important that survivorship support plans are implemented and coordinated addressing both medical and psychosocial aspects of care.

The planning process is not limited to doctors, and should be seen as a quality-related multidisciplinary team activity. Specialist nurses are in a unique position to assist with survivorship planning and provide the coordination of survivorship care. Through nurse led clinics, advanced nursing practice roles such as the nurse practitioner, advanced nurse clinical practice consultant and nurse clinical practice consultant can work alongside medical practitioners, benefiting both clinicians and patients.98 Survivorship plans should be dynamic and working documents, updated as patient circumstance changes and additional research becomes available.98,99
Box 15.2: Key elements of a survivorship support plan

- Patient diagnosis, age at diagnosis/treatment and stage.
- Treatment protocol/plan and exposures – including dates of therapy.
- Toxicities/morbidities experienced during therapy and potential long term toxicities.
- Guidelines for required screening for both recurrence and toxicities.
- Assessment of psychosocial/vocational/educational/financial needs.
- Recommended preventative behaviours/ interventions e.g. weight control, diet/nutrition, exercise, alcohol use, smoking, sun care, complementary medicine use, osteoporosis prevention, and immunisations.
- Information on the availability of community based psychosocial services e.g. an online searchable database of local resources according to postcode and/or links to national/international websites providing survivorship information and services.
- Contact information of the treating hospital and individual providers.
- Identification of a key contact and coordinator of continuing care.

Establishing partnerships with primary health providers, such as GP’s, local community health services, is required to achieve quality survivorship care in the health care issues for this growing population.

Other requirements for the implementation of survivorship planning include:

- Coordination of plans to ensure cohesive and efficient care, including an identified survivorship coordinator, i.e. specialist nurses such as nurse practitioners, nurse clinical practice consultants and advanced nurse clinical practice consultants
- Time to create and deliver plans
- Training of health professionals (inclusive of specialists) in needs of survivors and how to act on care plan recommendations.
- Research to expand the evidence base.
- Recognition of cancer as a chronic condition.
15.3. FURTHER INFORMATION

- **Peter MacCallum Cancer Centre Cancer.** Australian Cancer Survivorship Centre providing information for those who have successfully completed cancer treatment provides an example of a survivorship care plan template.

- **Cancer Council Victoria.** Currently developing a ‘comprehensive survivorship package’ including: DVD, booklet and a question prompt list, SCP for patient and for GP, Nurse-led ‘end of treatment’ session, and telephone-based follow up.

- **The Warwick Foundation.** Provides support to young adults with cancer aged 18-40, with a particular emphasis on their social and emotional wellbeing.

- **Oncolife: **Information about potential late effects of cancer treatment and survivorship care plans. All information is based on published, evidence-based guidelines whenever possible, and lacking those, consensus-based guidelines.

- **Cancer Survivor Toolbox:** [www.canceradvocacy.org/toolbox](http://www.canceradvocacy.org/toolbox)


- **Flinders Cancer Centre and the ACRF Cancer Prevention Unit:** [http://www.fcic.org.au](http://www.fcic.org.au)

- **Journey Forward,** for information on survivorship research and care plan: [http://www.asco.org](http://www.asco.org)

### RECOMMENDATIONS

- Establishment of partnerships between cancer specialists and primary health care providers, such as the patient’s GP, can help to facilitate improvements in achieving quality surveillance care plans for patients with head and neck cancer.
APPENDIX A: HEAD AND NECK CANCER PATHWAY RECOMMENDATIONS

Head and neck cancer in South Australia
>
Service providers should promote the use of culturally appropriate health preventative information (e.g. smoking cessation) available from Aboriginal Health Council of South Australia, and Aboriginal and Torres Strait Islander Liaison Unit at specific local hospitals.

Multidisciplinary and coordinated care
>
All patients with a head and neck cancer diagnosis should have access to a head and neck cancer coordinator throughout their cancer journey. These roles should be incorporated on sites with a head and neck cancer MDT.
>
Cancer Council resources, including the brochure ‘A multidisciplinary team approach to cancer care’, should be used as standard practice.

Supportive care (General)
>
Health professionals should be trained in supportive care screening to encourage inclusion of supportive care issues as part of multidisciplinary care.
>
Patient diaries should be implemented as standard care as a means of providing practical information about head and neck cancer treatment. Use of patient diaries requires continual qualitative evaluation that includes consumer involvement.
>
The use of health-related quality of life (HRQOL) measures in clinical practice, such as the University of Washington Quality of Life version 4 (UWQOLv4), is recommended.
>
The NCCN Distress Thermometer in automated electronic (touch-screen) format may be used to screen patients with results scored and transcribed so that information is readily available to guide the consultation. QUICATOUCH has been found to be effective in monitoring patients and increasing the number of new patients receiving timely and appropriate psychological treatment.

Supportive care (Specific needs of patients with head and neck cancer)
>
Nutritional screening, referral processes and clinical practice during and post-treatment needs to be standardised across the public and private sector. All patients with head and neck cancer should be screened using the validated MUST screening tool on admission and in outpatients.
>
All patients should have their weight recorded weekly as inpatients, and at each outpatient visit.
>
At-risk patients should receive early nutritional intervention by a dietitian with experience in treating patients with head and neck cancer (GRADE C).
>
Funding and access to home enteral nutritional (HEN) services should be equitable across greater metropolitan and rural South Australia.
>
A template should be developed to transfer information about supportive care needs of patients with head and neck cancer and their treatment plans at discharge. This includes transferring information between hospitals, to GPs and to community health staff. Ideally, this information should be available in electronic form and should provide up-to-date patient information for the head and neck MDT.
>
Patients having surgery to the tongue, palate or larynx, or radiotherapy, should be referred to a speech pathologist for assessment of voice, communication and swallow.
Dietetic and speech pathology resources required for best practice care of patients with head and neck cancer should be benchmarked. Long-term needs of patients and carers must be supported with adequate numbers of specialist staff.

Acute sector health professionals should participate in professional development and mentoring programs for rural cancer care health workers. This may include: peer shadowing; telemedicine support; and contribution to competency-based training for rural speech pathologists and dietitians.

Nurses working in oncology departments who are providing complex care for patients with head and neck cancer should have advanced standards and competencies in plastics, wound care and tracheostomy management. Oncology nurses working in radiotherapy day units should demonstrate a high level of clinical proficiency in a range of procedures, treatments and interventions that are evidence based, and based on Australian Nursing and Midwifery Council (ANMC) competencies.

Tracheostomy equipment (e.g. humidification, suction, speech aids) may be required by patients for an extended period on discharge from hospital. Subsidised funding should be available for these resources. Patients should also be given a listing of sources from which equipment can be accessed in the community.

Prevention and minimising risk

Aboriginal health services, Aboriginal Health Workers and health professionals working with culturally and linguistically diverse communities should be supported to promote interventions to encourage smoking cessation, reduction in high-risk alcohol intake, and promotion of regular ‘health’ or ‘dental’ checks.

Screening and early detection

All individuals with suspected symptoms of head and neck cancer should be referred to a head and neck cancer specialist within 2 weeks of identification by a GP / dentist.

The process for notification to a GP or Dentist should be initiated within 24 hours of referral to a head and neck cancer specialist if the patient does not arrive.

Early referral should be made to a Head and Neck Cancer care co-ordinator to address concerns while awaiting confirmation of a diagnosis.

Health professionals (GPs, dentists, pharmacists, community nurses and GP practice nurses) should be aware of ‘red-flag’ symptoms, risk factors for head and neck cancer, and surveillance of high-risk groups. All people identified in the ‘urgent referral’ category with symptoms and associated high-risk lifestyle behaviours consistent with head and neck cancer should be triaged for rapid access for investigations.

Further research is needed to identify and address reasons for delayed reporting of symptoms and reluctance to seek medical care by some population groups.

A benchmark of 4 weeks from GP identification of head and neck cancer symptoms to GP referral to a head and neck cancer specialist should be used.

Definitive treatment should start within 62 days of urgent GP referral.
Diagnosis and staging

- Synoptic reporting should be implemented as the standard for histopathologists evaluating head and neck/salivary gland malignancy.
- Synoptic reporting templates should be reviewed at least every 2 years to ensure prognostic relevant data are included and up to date.
- Collection of defined national minimum dataset on all head and neck cancer patients should be mandated through a national model.
- It is recommended that tissue samples for diagnosis (histology, cytology, molecular markers) are obtained within 1 week of consultation with the specialist to ensure treatment is not delayed for those with a potentially curable cancer.
- Staging investigations (note exceptions) should be done within 1 week of tissue confirmation of head and neck cancer.
- PET-FDG (used with clear guidelines) should be a routine tool for patients with locally advanced disease, where treatment intent is curative.
- Radiology and Pathology departments require referrals for patients to be discussed at the MDT meeting at least 2 days before the meeting to enable collation and photography of slides, and ordering of additional tests if needed. If slides need to be sourced from another local laboratory, 5 working days is recommended. This can be modified for urgent requests.

Presentation at Head and Neck MDT meeting

- All patients with a diagnosis of head and neck cancer should be discussed prospectively at an MDT meeting within 14 days of a confirmed diagnosis.
- MDT meetings must be appropriately resourced. This includes administrative support and an MDT meeting coordinator and / or administrative support (administrative A03 level). Administrative processes should be standardised with clear protocols.
- TNM staging of head and neck cancer cases discussed at the MDT meeting should be recorded for all cases.
- A copy of the treatment plan, including any revisions made following patient discussion, should be sent to the referring GP within 3 working days of the MDT meeting. A copy should also be placed in the patient’s case file and sent to the specialist responsible until care is formally referred and passed on to another practitioner.
- Where possible, patients should be offered clinical trial enrolment.
- Improvements to telehealth facilities will facilitate initial patient assessment and post-treatment follow-up (where clinically appropriate) with GPs.

Treatment

- Surgical treatment of head and neck cancers should be carried out by appropriately trained and credentialed surgeons who maintain a full patient audit and clinical database available for peer review. Peer review should occur at regular defined intervals.
- Head and neck cancer treatments should be provided within an accredited institution with access to supporting facilities as indicated by the level and intensity of therapy required.
- A plastic surgeon should be present at the MDT meeting for identification of patients who may benefit from reconstruction and to advise the MDT of suitable options.
Patients who are candidates for reconstructive surgery should be assessed in person by the plastic surgeon, alongside the excisional surgeon, to formulate an agreed plan and approach. The plastic surgeon can then assess the patient's suitability for reconstruction and advise them of the options.

Following surgery, inpatient progress with reference to reconstruction should be monitored by the plastic surgical team until discharge to ensure optimal care for a successful recovery and return to function.

Following discharge, all reconstructed patients should be assessed by the plastic surgical team as an outpatient with particular reference to outcome and function of the reconstruction; this follow-up assessment should be in addition to follow-up care for the purpose of cancer surveillance.

Chemotherapy should be given according to established evidence-based protocols and practices that are standardised across SA.

Medical oncologists providing chemotherapy for patients with head and neck cancer should be accredited by the RACP and credentialled by their institution for practice in this area.

Chemotherapy with curative intent may be considered in the following situations using a cisplatin-based therapy:

- induction chemotherapy for advanced stage hypopharynx SCC
- induction chemotherapy for tumours, other than hypopharynx, when a tumour is sufficiently advanced as to require prompt treatment whilst awaiting definitive surgery or chemoradiotherapy and the patient is considered fit enough to tolerate treatment
- definitive chemoradiotherapy where the patient has one of the following: unresectable disease, requires organ preservation, is deemed medically unfit for surgery or declines surgery
- post-operative chemoradiotherapy should be considered for patients with poor prognostic features, i.e. positive surgical margins, extracapsular nodal spread of cancer; other high-risk factors with lesser evidence may be taken into consideration, such as perineural/vascular invasion, large number of nodes, and should be decided on an individual basis after discussion in the MDT meeting

For patients considered for curative chemoradiotherapy in whom cisplatin is contraindicated, the option of cetuximab with radiotherapy should be considered.

Patients receiving combined modality chemoradiotherapy (or cetuximab) with curative intent should be counselled as to the increased toxicity of combined treatment compared with radiotherapy alone.

Patients receiving systemic treatment should be seen by a medical oncologist before each dose of chemotherapy and, in the case of cetuximab, at least fortnightly. Blood tests should be conducted before administration of each new dose of systemic treatment and should include a full blood picture, biochemistry, magnesium and potassium, with treatment adjusted accordingly.

Where the patient is considered to have incurable disease, the patient should be assessed by a medical oncologist as to their suitability for palliative chemotherapy. This generally requires an ECOG performance status of 0–2. Palliative chemotherapies currently funded in Australia have minimal impact on survival but may enhance quality of life.

Radiation oncologists (FRANZCR or equivalent) and departments providing radiotherapy for patients with head and neck cancer should proceed according to established protocols and practice standards outlined for the prescription and delivery of radiotherapy.

The time from decision to treat to the actual start of treatment should not exceed 4 weeks.
The time from surgery to post-operative radiotherapy should be approximately 42 days.

Special needs dentists, preferably with knowledge and experience of oral implantology, should be a core member of the head and neck MDT.

Referral to a special needs dentist should preferably be made at the time of diagnosis to assist with treatment planning.

Preventative oral care must be delivered to all patients during and after treatment for head and neck cancer.

At the end of treatment, a summary of therapy and recommendations for follow-up should be provided to the patient and sent to patient’s personal community dentist.

Complementary therapy

A clear documented surveillance plan should be completed with an identified specialist for all patients following completion of treatment for head and neck cancer. The surveillance plan should be provided to the patient and their GP.

All patients with recurrent head and neck cancers should be referred to the head and neck MDT meeting for discussion and consideration of interventions, including chemotherapy and/or radiotherapy, and to review the plan for ongoing best supportive care.

Cancer recurrence

A clear documented surveillance plan should be completed with an identified specialist for all patients following completion of treatment for head and neck cancer. The surveillance plan should be provided to the patient and their GP.

All patients with recurrent head and neck cancers should be referred to the head and neck MDT meeting for discussion and consideration of interventions, including chemotherapy and/or radiotherapy, and to review the plan for ongoing best supportive care.

Palliative care

A palliative approach should be a core principle of care for all treating clinicians

A referral to specialist palliative care should be made early in the course of disease for people with complex and unmet needs

All patients and their families and/or caregiver should have access to specialist palliative care services if required

All patients and their families and/or caregivers would benefit from having a clinician who provides case coordination to ensure that they can navigate the health system

All patients and their families and/or care giver(s) require information regarding bereavement support services, while some will require specific assessment and support

Survivorship

Establishment of partnerships between cancer specialists and primary health care providers, such as the patient’s GP, can help to facilitate improvements in achieving quality surveillance care plans for patients with head and neck cancer.
APPENDIX B: KEY PRINCIPLES OF CANCER CARE

Underpinning the cancer pathway are key principles that support each stage of the pathway.

**Patient centred care**

- Patients and their families/care givers are encouraged to be involved as active participants in care planning and decision making. Ultimately treatment decisions rest with the patient or designated person. This requires information and discussion to be provided in their preferred language and in a manner that is sensitive to their culture.

**Safe and high quality care**

- Cancer care is complex, involving a range of specialist providers and health professionals with varied clinical expertise. To ensure safe and high quality cancer care it is essential for health professionals to possess the technical skills and experience to undertake the relevant aspects of cancer care and have access to appropriate infrastructure to support such care.

**Multidisciplinary care**

- Best practice in cancer care involves multidisciplinary treatment planning and multidisciplinary care delivery.

- Effective multidisciplinary approaches in the management of patients with cancer have demonstrated positive outcomes, including increased survival, a greater understanding that a comprehensive team is providing care, a greater likelihood of receiving care that is in accordance with clinical practice pathways (including psychosocial and practical support), increased access to information for patients and increased patient satisfaction with care.

**Supportive care**

- Patients with cancer have psychological and social needs that are frequently undetected and unmet, and have the potential to cause long-term distress.

- Supportive care includes the acknowledgement of all domains of patient needs – physical, psychological, social, informational and spiritual – that may be required to support the patient and their families/caregivers.

**Care co-ordination**

- Patients require co-ordination of their health care. A variety of strategies have been shown to improve co-ordination of care and these include multidisciplinary team meetings, clinical protocols, access to cancer nurse specialists and utilisation of appropriate performance indicators.
APPENDIX C: EXPANDED VIEW OF SA PATIENT INFORMATION PATHWAY

The Head and Neck Cancer Care Coordinator will support you throughout your cancer journey, from diagnosis to survivorship or end of life care. They will provide you with verbal / written information about investigations, treatment, and complementary therapies. They will ensure that you and your family are supported at all steps of your head and neck cancer pathway.

Local Support Services
- RAH / FMC Maxillofacial / Head and Neck Clinic
- Supporting services such as the surgical team, a head and neck cancer care coordinator (key contact person), dietitian, speech pathologist, medical oncologist, social worker, psychologist involved in counselling
- CANCER website provides updates of cancer services in SA, and a directory of services at www.cancer.sa.gov.au
- Cancer Council SA provides counselling services with trained cancer liaison nurse or by telephone, as well as other support services. Call the Cancer Council Helpline on 13 11 20
- Assistance for patient travel can be sought for eligible patients through the Patient Assistance Scheme (PATS). Contact your local hospital for further information.

Abbreviations
- ENT: Ear, Nose, Throat
- RAH: Royal Adelaide Hospital
- FMC: Flinders Medical Centre
- ASH: Alice Springs Hospital
- RDH: Royal Darwin Hospital
- LMS: Lyell McEwin Hospital
- MDM: Multidisciplinary Team Meeting
- FPH: Flinders Private Hospital
- AWCC: Allan Walker Cancer Centre
- HSN: Head and Neck
- RGH: Repatriation General Hospital
- CT: Computed Tomography
- MRI: Magnetic Resonance Imaging
- PET: Positron Emission Tomography

End of life care is a holistic approach to the physical, psychological, emotional, and spiritual needs of you and your family.
Your GP / surgeon / local palliative care services / HN Cancer Care Coordinator will continue to provide care and support for you during this time.
Metropolitan: LMS, QEH, RGH, FMC
Country: Mt Gambier, Pt Lincoln, Berri, Whyalla, Pt Augusta, Eyre Peninsula, Riverland
APPENDIX D: SAFETY AND QUALITY KEY PERFORMANCE INDICATORS

Below are the key quality indicators representing all the stages of head and neck cancer care: including referral, diagnosis, treatment, supportive care, post treatment follow-up and survivorship.
(Based on Performance Indicator Framework for SA Cancer services, Communio 2010)

Referrals
- GP referral form, referral process, is the GP providing, enough detail on referral form, completeness of information.
- Percentage of patients with an urgent new head and neck cancer referral from their GP waiting greater than 2 weeks to see the specialist
- Percentage of patients who are referred to the head and neck cancer coordinator

Diagnosis
- 2-week time point from confirmed diagnosis to presentation at the multidisciplinary team meeting.
- 100% of pathology reports in synoptic format
- 100% of patients with radiology staging reports where radiology reports are compliant with structured radiology reporting guidelines
- Percentage of patients referred to the multidisciplinary team with documented clinical staging
- Percentage of patients who are Stage 4 at diagnosis

Treatment
- Palliative care referral (number of direct referral to palliative care without surgical, medical oncology or radiation oncology referrals)
- 100% of head and neck cancer patients discussed at MDM
- Number of specialist cancer nurses who can demonstrate meeting ANMC competency standards in the management of head and neck cancer
- 100% of patients are offered enrolment in a clinical trial, where appropriate
- Percentage of patients with documentation regarding the patient’s use of complementary therapies
- 100% of newly diagnosed patients have a documented multidisciplinary care plan resulting from the MDM
- 100% of patients completing a treatment episode, have a comprehensive treatment summary (or discharge summary) sent to their nominated GP within 3 days of completion of treatment
- Percentage of patients having a dental assessment during and post treatment

Supportive care
- 100% of all newly diagnosed patients screened for supportive care needs
- Evidence of screening in patient record for 100% of patients
- Appropriate referrals made in response to needs identified via supportive care screening
- Increase in the number of supportive care needs being addressed via referral to appropriate service/resource
- Increase in staff confidence in identifying supportive care needs measured by satisfaction surveys

Survivorship
- 100% of patients have a documented survivorship plan on completion of treatment
- 100% of patients who are admitted to hospital have an advance care directive

Follow-up
- 100% of relapsed/progressive disease patients have a documented multidisciplinary care plan resulting from a multidisciplinary team meeting
- Quality of life surveys completed following treatment
- Follow up from all relevant health professionals including surgical, radiotherapy and oncology health professionals.
APPENDIX E: BENEFITS AND PRINCIPLES OF MULTIDISCIPLINARY CARE

BENEFITS OF MULTIDISCIPLINARY CARE

- Increased provision of evidence-based care in accord with clinical practice pathways (where available) with implications for both clinical outcomes and cost effectiveness
- All treatment options are considered and treatment plans are individualised to each patient
- Improved referral pathways
- Decreased variation in care
- Increased referrals for psychosocial support
- Increased discussion of patient eligibility for clinical trials
- Enhanced clinical education opportunities
- Opportunity for health professionals to interact.

Positive outcomes identified for patients include:

- Increased patient satisfaction with care
- Increased survival when care is managed by a multidisciplinary team
- Increased access to information for patients, particularly psychosocial and practical support
- Increased perception by the patient that care is being managed by a team

MULTIDISCIPLINARY CARE PRINCIPLES

1. A team approach

   - There is an established multidisciplinary team that comprises relevant core disciplines, including allied health and psychosocial health specialists.
   - The general practitioner is regarded as a team member and effective communication processes between the multidisciplinary team and the general practitioner are established.
   - Effective communication processes exist with access and referral links between all core and non-core team members.

2. Communication among team members

   - All the core team members regularly attend multidisciplinary team meetings (MDM) to provide input into diagnostic, treatment, supportive and palliative care planning.
   - Processes are in place for communication for treatment recommendations and care plans
   - The OACIS or EPAS clinical summary (or alternative summary) letter enables electronic communication of treatment recommendations and care plan between core MDM members and members of the treating team. Summaries and letters need to be communicated in a timely manner with the patient’s GP and private practitioners who do not have access to EPAS.

3. Access to the full range of therapeutic modalities for all patients, regardless of geographical remoteness or size of institution

   - All patients regardless of where they live will have information about and access to relevant treatment and services.
Clinical trial involvement is considered for all eligible patients who will be undergoing cancer treatment.

4. Provision of care in accord with agreed standards/pathway

- Informed decision making is guided by current best practice principles.
- All relevant diagnostic results, reports and pathology and radiology images are available for MDM.
- Professional development activities for all MDM members are offered and supported.

5. Involvement of patients in decisions about their care

- Informed consent is obtained prior to a MDM.
- Patients are informed of the MDM care and billing processes through Medicare for their treatment planning.
- Patients are informed of the MDM; recommendations and provided with information about all aspects of their treatment.
- Patients are routinely provided with suitable information about and access to supportive care services.
APPENDIX F: FACTSHEET FOR GENERAL PRACTITIONERS

GPs play an important role in the early detection, treatment and follow-up care of patients with cancer and in communication of prevention messages.

THE ROLE OF THE GP

GPs provide both clinical and supportive care to patients with cancer.

<table>
<thead>
<tr>
<th>Clinical care</th>
<th>Supportive care</th>
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</thead>
<tbody>
<tr>
<td>&gt; Recognition of signs/symptoms</td>
<td>&gt; Provision of appropriate information on diagnosis and treatment to patients and carers</td>
</tr>
<tr>
<td>&gt; Documentation of history and clinical findings</td>
<td>&gt; ensuring rural/remote patient receive appropriate information regarding services</td>
</tr>
<tr>
<td>&gt; Initiating and review of results of initial investigations</td>
<td>&gt; referral to psychosocial and practical support when required for patients and care givers</td>
</tr>
<tr>
<td>&gt; Prompt referral to appropriate specialist</td>
<td>&gt; support during palliative and end of life care</td>
</tr>
<tr>
<td>&gt; Patient assessment and surveillance throughout treatment</td>
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<tr>
<td>&gt; Monitoring of long-term treatment side effects</td>
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<tr>
<td>&gt; Monitoring of signs/symptoms of recurrence post-treatment</td>
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A full description of the role of a GP in the management of patients with cancer is detailed on page 10 of the South Australian Head and Neck Cancer Pathway.

RECOGNISING SIGNS AND SYMPTOMS

Early detection of cancer through recognition of symptoms and appropriate and timely referral to specialist care plays a critical role in the quality care, treatment and survivorship for cancer patients.

The signs and symptoms of head and neck cancer can include:

> hoarseness
> ulceration of oral/oropharyngeal mucosa
> persistent oral swellings
> red or red and white patches of the oral mucosa
> dysphagia
> unexplained tooth mobility not associated with periodontal disease
> non-healing dental extraction site
> unresolving neck masses
> cranial neuropathies, including unexplained facial weakness
> referred pain in the ear without evidence of local ear abnormalities
> orbital masses
> unilateral serosanguinous nasal discharge.

⚠️ Urgent referral from a GP/Dentist to a head and neck specialist should occur for patients presenting signs and symptoms persisting for more than 3 weeks.

⚠️ Suspicion should be further raised if the symptomatic patient is a heavy smoker or heavy alcohol user, aged over 45 years, and/or male.
ASSESSMENT AND INVESTIGATION

Investigations may be undertaken by a GP after urgent specialist referral has occurred.

> The decision about which clinical investigations should be undertaken by the GP may require discussion (by phone or e-mail) between the GP and specialist (or senior ENT Registrar in public hospitals).

> No biopsy should be carried out in a non-specialist environment.

Investigations must not replace or delay urgent specialist referral; negative investigation findings (such as negative imaging) do not exclude the presence of head and neck cancer.

A full description of the initial tests and assessments required to investigate a suspicion of head and neck cancer is detailed on pages 31–32 of the South Australian Head and Neck Cancer Pathway.

APPROPRIATE AND TIMELY REFERRAL

If cancer is suspected, referral to a specialist physician should be made as soon as possible.

A GP referral letter can be faxed, emailed or submitted via a web based referral technology. The most rapid form of referral technology is the Enterprise Patient Administration System (EPAS). A phone discussion is also strongly recommended to facilitate an urgent appointment.

The referral letter to a specialist physician should include:

> history of presenting signs (clinical history)
> recordings of current and previous weight
> past medical history, including current medications and allergies
> relevant psychosocial history
> all relevant investigations and imaging
> most appropriate contact details for patient, e.g. mobile phone number or the phone number of a relative or carer if the patient speaks limited or no English.

The patient should be see a specialist within 2 weeks of initial presentation

A full description of the process for referral of a patient with suspected head and neck cancer is detailed on page 32 of the South Australian Head and Neck Cancer Pathway.

A NOTE ON THE MULTIDISCIPLINARY TEAM

The GP is welcome to attend the multidisciplinary team (MDT) meeting if desired.

During the MDT meeting, an individualised treatment plan is developed for each patient, taking into account the patient’s preferences. This plan should be documented and communicated to the patient, their family and all treating clinicians, including the GP.
APPENDIX G: PRINCIPLES OF SUPPORTIVE CARE

Supportive care is an ‘umbrella’ term used for all health services (generalist and specialist) that may be required to support people with cancer and their families and/or care givers.

Research indicates that people with cancer who receive appropriate information and psychosocial interventions have lower rates of anxiety, mood disorders, nausea, vomiting, pain, as well as a greater knowledge and understanding about their disease and treatment. The type and degree of interventions to meet the supportive care needs for patients and their caregivers will vary throughout the cancer journey; many patients’ needs will be met adequately through the provision of general information, while some patients will require specialised intervention.

The spectrum of supportive care includes:

- management of physical symptoms and side effects across the cancer continuum from diagnosis through treatment to post treatment care
- management of psychosocial issues
- enhancing rehabilitation
- secondary cancer prevention
- promoting healthy lifestyles with health risk reductions strategies
- monitoring functional status
- survivorship support and care
- end of life care

PROVIDERS OF SUPPORTIVE CARE

All members of the multidisciplinary team have a role in the provision of supportive care. In addition the patient may have support from family, friends, support groups, volunteers and other community-based organisations.

ACHIEVING BEST PRACTICE IN SUPPORTIVE CARE

Supportive care service provision requires an initial assessment and identification of the patient’s specific needs. This is achieved through regular discussion and systematic review of the patient and their care givers. Regular reassessment is essential, as needs frequently change throughout the cancer journey.

This review process assists in identifying those patients who are experiencing significant levels of distress and are at higher risk of psychological morbidity, and facilitates appropriate referral for further assessment and specific interventions. The Australian Clinical practice guidelines for the psychosocial care of adults with cancer and the National Comprehensive Cancer Network’s clinical practice guidelines for distress management recommend the use of a validated screening tool such as the Distress Thermometer.

ESTABLISHING A SUPPORTIVE CARE MODEL

As a range of professionals and services provide supportive care, it is important to have in place:

- Patient’s and carers have their supportive care needs systematically identified as part of a multidisciplinary best-practice approach to cancer care
- A detailed assessment of supportive care needs will help identify those patients who require more specific one-one intervention and follow-up
> A clear referral pathway to specialised supportive care services
> A skilled workforce with the ability to assess patient needs, deliver support and/or enable referral onto specialist supportive care providers at suitable points in the patient’s cancer journey
> Promotions of supportive care as integral components of cancer service delivery, including information about the range of professional services available so that patients can self-refer or self-identify a need.
> Adequate communication between health services, to enhance referral and linkage of supportive care services.

Other specific information needs may include:
> assistance with smoking cessation may be required; this is particularly relevant prior to surgery to reduce the likelihood of post-operative complications (information is available from the head and neck cancer care co-ordinator and the Quitline on 13 78 48)
> Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities have specific informational needs that require culturally appropriate resources (Aboriginal Cancer Care Co-ordinators/ local Aboriginal Health Service may be able to assist patients and caregiver(s) in their region).

COMMUNICATION WITH PATIENT AND CARE GIVERS
Patients require verbal and written information that is culturally appropriate and may require access to a qualified interpreter (accredited by the National Accreditation Authority for Translators and Interpreters (NAATI). Information required includes details about the disease, preventative actions, the reasons for and likely effects of diagnostic procedures, treatment options (including known risks and potential adverse effects), and information about effective coping strategies. Patients and carers should receive both individual support and guidance and well-produced, culturally appropriate information leaflets, or quality web-based information.

It is recommended that health care providers ask patients if they want additional information and discuss how much they wish to be involved in decisions about treatment. Determine the patient’s needs and preferences regarding information about treatment, and encourage family members, caregivers and/or others who may provide support to the patient during consultations. Specific instructions for self-care may enable patients and family members to maintain their desired level of independence throughout the cancer care journey.

All health professionals involved should know what information has been given to each patient. A record of this, along with the patient’s preferences for information and involvement in decision-making, should be included in the notes and given to the patient’s general practitioner, together with a comprehensive summary of the management plan. Communication needs to be effective, with fast and efficient links.
## APPENDIX H: CANCER RESOURCES AND SERVICES IN SOUTH AUSTRALIA

### CANCER RESOURCES

<table>
<thead>
<tr>
<th>Organisation</th>
<th>About</th>
<th>Resources</th>
<th>Website</th>
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<tbody>
<tr>
<td><strong>Resources for the general population</strong></td>
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</table>
| **Cancer Australia**         | Cancer Australia works to reduce the impact of cancer and improve the well-being of those diagnosed by ensuring that evidence informs cancer prevention, screening, diagnosis, treatment and supportive care. | > Factsheets and statistics sheets on different cancer types  
| **Cancer Council South Australia** | An independent, non-profit organisation driving research into cancer and supporting South Australians affected by cancer.                                                                                 | > Services include **information resources** on cancer, its treatment, side effects, and medical terminology, support services such as counselling, self-care programs, accommodation and research.  
> CCSA also provides links to other reliable cancer information websites, along with an online library. | [www.cancersa.org.au](http://www.cancersa.org.au)                                                                                                                                         |
| **Cancer Council Helpline**  | Nurses and health counsellors available via a telephone support service.  
Cancer Connect - for telephone peer support from people who have had cancer experiences.                                                                                       | > Telephone help line : 13 11 20  
> Email: chl@cancersa.org.au |                                                                                                                                              |                                              |
| **Cancer Council Australia** | The leading independent funders of cancer research in Australia (through National and state-based organisations).  
Provide evidence-based, up to date information for consumers.                                                                                                                       | > **Fact sheets on a variety of cancer issues** including early detection, diagnosis and treatment, living with cancer and lifestyle advice. | [www.cancer.org.au](http://www.cancer.org.au) |
<p>| <strong>Health insight</strong>           | <em>healthinsite</em> is a non-commercial, government-funded health                                                                                                                                     | &gt; <strong>Fact sheets</strong> on a variety of health conditions | <a href="http://www.healthinsite.gov.au/">http://www.healthinsite.gov.au/</a>                                                                  |</p>
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<tr>
<th>Organisation</th>
<th>About</th>
<th>Resources</th>
<th>Website</th>
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<tr>
<td></td>
<td>information service, operated by Healthdirect Australia. It aims to</td>
<td>&gt; <strong>Tips for healthy living</strong> at different stages of life</td>
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<tr>
<td></td>
<td>improve the wellbeing of all Australians by providing easy access to</td>
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<td></td>
<td>quality health information and services.</td>
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<tr>
<td><strong>Resources for Aboriginal and Torres Strait Islander population</strong></td>
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<tr>
<td>Australian Indigenous Health</td>
<td>A national website with information for both the public and health</td>
<td>&gt; <strong>Fact sheets</strong> on a variety of health conditions</td>
<td><a href="http://www.healthinfonet.ecu.edu.au">www.healthinfonet.ecu.edu.au</a></td>
</tr>
<tr>
<td>Info Net</td>
<td>professionals. It promotes knowledge and information sharing on all</td>
<td>&gt; Information on prevention and risk factors</td>
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<tr>
<td></td>
<td>health issues relevant to ATSI people.</td>
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<tr>
<td>A Cancer Journey</td>
<td>A Cancer Story for Remote Indigenous Patients In the NT</td>
<td>An information DVD available in the following languages; English, Kriol,murrinh-Patha, Yolngu-Matha, Warlpiri, Pitjantjatjara</td>
<td><a href="http://wwwcancercouncilnt.com.au">wwwcancercouncilnt.com.au</a></td>
</tr>
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## CANCER SERVICES

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Location</th>
<th>Website</th>
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<tbody>
<tr>
<td><strong>Aboriginal Health Liaison Units located in Adelaide hospitals.</strong></td>
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<tr>
<td>The Queen Elizabeth Hospital Aboriginal Liaison Officers</td>
<td>Woodville Road, Woodville, SA</td>
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<tr>
<td>Lyell McEwin Hospital, Muna Paidendi Aboriginal Health Team</td>
<td>Haydown Road, Elizabeth Vale</td>
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A list of Community Health services in SA is available at the following web sites:
- [http://www.caesa.org/commhealth.html](http://www.caesa.org/commhealth.html)
- [http://www.caesa.org/acsd.htm](http://www.caesa.org/acsd.htm)

## Services for culturally and linguistically diverse populations

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Location</th>
<th>Website</th>
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<tbody>
<tr>
<td>Migrant Health Service</td>
<td>21 Market Street, Adelaide 5000</td>
<td>&gt;</td>
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<tr>
<td>Organisation</td>
<td>Location</td>
<td>Website</td>
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<td>--------------------------------------------------</td>
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<tr>
<td>Multicultural Communities Council of SA (MCC)</td>
<td>113 Gilbert Street, Adelaide 5000</td>
<td><a href="http://www.multiwebsa.org.au">www.multiwebsa.org.au</a></td>
</tr>
<tr>
<td>Translating and Interpreting Service (TIS)</td>
<td>Casseldon Place, 2 Lonsdale Street, Melbourne VIC 3000</td>
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<tr>
<td>Services for Women</td>
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<tr>
<td>Services include women’s health line and counselling</td>
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PALLIATIVE CARE SERVICES

Palliative care services are available throughout South Australia. Up to date contact information can be found on the Palliative Care Council of SA website (link below).

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Location</th>
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<tbody>
<tr>
<td>Palliative Care Council of SA Inc</td>
<td><a href="http://www.pallcare.asn.au">www.pallcare.asn.au</a></td>
</tr>
<tr>
<td>Statewide Services</td>
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</tr>
</tbody>
</table>

Metropolitan services

> Northern Adelaide Palliative Care
> Central Adelaide Palliative Care
> Southern Adelaide Palliative Care

Country services

For country referrals to palliative care, please direct to your local community health service. The exception is for referrals to the Inner North, Lower North and Yorke Peninsula areas. These are to be directed to Health Link. Phone: 1800 003 307; Fax: 8561 2142.

> Adelaide Hills Palliative Care (Mt Barker)
> Inner North Palliative Care (Barossa/Gawler)
> Ceduna Palliative Care
> Kangaroo Island Palliative Care
> Lower North Palliative Care (Clare)
> Murray Mallee Palliative Care (Murray Bridge)
> Naracoorte Palliative Care
> Port Augusta Palliative Care
> Port Lincoln Palliative Care
> Port Pirie Palliative Care
> Riverland Palliative Care (Barmera)
> South Coast Palliative Care (Victor Harbor)
> South East Palliative Care (Mt Gambier)
> Whyalla Hospital Palliative Care
> Yorke Peninsula Palliative Care (Wallaroo)
APPENDIX I: REFERRAL FOR PSYCHOSOCIAL CARE

It is important to screen patients for elevated distress and emotional concerns at every medical appointment, but particularly at times of increased vulnerability, e.g. at time of diagnosis, prior to commencement of treatment or at the end of treatment, discharge from hospital, surveillance appointments and recurrence / progression of disease. It is common for people who are experiencing increased distress to have difficulty recalling and remembering information. To assist in reducing anticipatory anxiety, be sure the patient understands their disease and treatment options. Refer the patient to education materials and advise patients and their families that times of transition may bring increased vulnerability to distress.

Before referring for psychosocial care please consider the following:

- Is the person and/or family member experiencing an acute exacerbation in distress following a period of increased vulnerability? (as listed above)
- Is the person’s distress directly related to:
  - Sadness associated with loss of usual good health
  - Preoccupation with thoughts about illness and treatment
  - worry about future
  - worry about the impact the illness is having on their family
  - relationship or family issues
- Are there significant practical concerns for person? (e.g. financial stress, transport issues, power of attorney, end of life decisions, etc)
- Is the person experiencing chronic elevated distress that is impacting on pain or symptom control or on their normal functioning or ability to complete cancer treatment
- Has a past history of mental health concerns
- Has trauma history or symptoms (i.e. PTSD)
- Is experiencing severe anxiety related to their medical condition
- Is hyper vigilant, experiencing panic attacks or highly irritable
- Appears to be depressed or reporting suicidal ideation
- Is describing illness specific fears and phobias (i.e. needle phobia, hypochondriasis)
- Is exhibiting behaviours that are challenging to manage (i.e. aggression)
- Is reporting issues with body image or sexuality concerns
- Is concerned by chronic disruption to sleep, appetite and/or concentration
- Is the person’s primary presentation psychiatric in nature?
- Are there imminent risk issues? (e.g. suicidal plan/intent or aggression)
- Does the person have a previous psychiatric history or do they have current psychiatric input?
- Is there evidence of a thought disorder or psychosis?
- Is the person non-compliant?
- Are there signs or symptoms of suspected delirium?
- Does the person appear to have borderline cognitive status?
- Is there uncertainty about the nature and extent of cognitive issues?
- Is there difficulty identifying or distinguishing possible diagnoses/etiologies?
- Has the person experienced any particular event that may impact on their cognitive function? e.g. brain injury, cancer metastases to brain?
- If the person is over the age of 65, has the person been triaged to Geriatric Medicine for formal assessment?

Consider consulting or referring to these Disciplines:

Social Work
- Supportive counselling for patient and family
- Linking with external psycho-social supports
- Support groups and/or individual counselling
- Family meetings
- Grief counselling

Clinical Psychology
- Dependent on the presenting complaint, psychological intervention may include a combination of formal assessment, cognitive behavioural therapy, hypnotherapy, management suggestions, and other relevant therapeutic interventions.

Psychiatric Referral
- Formal Psychiatric Assessment and Review (e.g. history/medications)

Clinical Neuropsychological
- Formal Neuropsychological Assessment
APPENDIX J: HEAD AND NECK CANCER DIETETIC PATHWAY

Head and Neck Cancer Dietetic Pathway; Surgery or Palliation

**H&N MDM**
Dietitian (DN) Attendance

**Planned for surgery**
- Nursing main nutrition screening using
  - Malnutrition Universal Screening Tool (MUST)
  - Malnutrition Screening Tool (MST)

**Planned for Palliation**
- Review prognosis & nature of any dysphagia at MDM

**Dietetic intervention**
- Nutrition intervention directed by prognosis
- Maximise QOL & comfort with food fortification/texture modification/oral supplementation

**Dietitian Assessment**
- Patient Generated Subjective Global Assessment Tool (PG-SGA) / SGA conducted by DN
- Initiate pre-op nutrition support in malnourished population
- Consider Prophylactic gastrostomy
- See Prophylactic Gastrostomy Criteria

**Surgical intervention**
- Laryngectomy
- Glossectomy
- Mandibulectomy
- Floor of Mouth Resection
- Maxillectomy
- Any flap/graft/skin reconstruction
- Anyone MDM for >24hrs and requiring NET feeding post-op

**Automatic DN Referral**
DN to assess & initiate NET feeding post-op:
- >125kJ ~ 180kJ/kg/day
- 1.2 – 1.5g/kg/day
- Standard polymeric fibre feed
- If immunonutrition to be used post operatively, it should be given for a minimum of 7 days

- Collaborate with MDM (Surgeons, Speech Pathology) on how & when oral intake is to resume
- Ongoing dietetic management with view to prevent weight loss

**Ongoing significant dysphagia or inadequate oral intake consider Prophylactic Gastrostomy – see Prophylactic Gastrostomy Criteria**

**No adjuvant treatment planned**
DN follow-up in 6-8 weeks and thereafter until patient stable.

**Adjuvant treatment planned**
Refer to RTx + CTx Pathway
APPENDIX L: SA MINIMUM DATA SET FOR HEAD AND NECK CANCER DATABASE

The following is modified from the British Association of Head and Neck Oncologists 1999 document *BAHNO National Minimum and Advisory Head and Neck Cancer Data Sets* (www.bahno.org.uk/docs/dataset.doc)

**Minimum dataset**

A. Demographics and Risk Factors

1. Name (Surname, Forename; Name at birth)
2. Medical Record Number (Public institution, other)
3. Date of Birth
4. Age at diagnosis
5. Gender
6. Address at time of diagnosis (Physical, Postal)
7. Marital status at time of diagnosis
8. Ethnic origin
9. History of non-head and neck cancer
10. Smoking (pack year history, current / ex, years since cessation, mode, type)
11. Alcohol (beer / wine / spirits, quantity per week, current / ex, years since cessation)
12. Betel / Chewing tobacco/other
13. P16 immunotyping pathology marker
14. BMI (weight kg, height m)

B. Tumour

1. Date of first symptom
2. Date and source of primary referral
3. Date first seen by specialist/ first clinic
4. Original, recurrence or unknown
5. Date of Diagnosis
6. Treating specialist
7. Primary site; Laterality (L, R, midline, bilateral)
8. Subsite
9. State if recurrence; Type of recurrence; Date of initial tumour diagnosis
10. Final pre-treatment T stage
11. Final pre-treatment N stage
12. Final pre-treatment M stage
13. Imaging modality
14. Workup clinical or radiologic differences to staging
15. Final pre-treatment overall Staging (I-IV)
16. Biopsy histology tumour type
17. Grade of tumour differentiation
18. Biopsy thickness (mm); depth (mm); margins (mm)
19. Patient performance status at presentation (WHO)

   (0=fully active; 1=restricted in heavy activity; 2=ambulatory and capable self-care; 3=capable of only limited self-care; 4=completely disabled)

20. Date of MDM , and decision to treat
21. Treatment offered
(C=curative; P=palliative; R=refusal of treatment by patient; S= supportive treatment; U=unknown,)
C. Surgery and pathology

1. Date of surgery
2. Date of discharge
3. Lead surgeon responsible
4. Main surgical procedure
5. Second surgical procedure
6. Third surgical procedure
7. Fourth surgical procedure
8. Fifth surgical procedure
9. Sixth surgical procedure
10. Date of pathology
11. Any frozen section
12. Surgical specimen pathology
13. Number positive nodes / total – specified as (a) for each side, (b) per level, (c) overall total
14. Differentiation
15. Pathological T stage
16. Pathological N stage
17. Pathological M stage
18. Pathological stage overall
19. Tumour thickness and depth (mm)
20. Margins (microscopic), esp. clear and close (mm, site)
21. Anatomical site (central/R/L)
22. Invasive front
23. Extracapsular spread of lymph nodes
24. Perineural invasion
25. Vascular/lymphatic invasion
26. Bone/cartilage invasion
27. Extrathyroid invasion
28. Complications or morbidities

D. Radiotherapy

1. Start date
2. Finish Date
3. Oncologist responsible
4. Hospital for radiotherapy
5. Site treated
6. Treatment dose (Gy) and total fractions \( P=\text{primary}; N=\text{nodes}; C=\text{primary and nodes}; M=\text{metastases}; O=\text{other} \)
7. Complications, morbidities or breaks

E. Chemotherapy

1. Start date first cycle
2. Start date last cycle
3. Hospital treatment
4. Oncologist
5. Number of cycles given
6. Complications, morbidities or breaks

F. Performance status and Quality of Life

1. Performance status at one year from date of diagnosis (0=fully active; 1=restricted in heavy activity; 2=ambulatory and capable self-care; 3=capable of only limited self-care; 4=completely disabled)
2. NGT / Gastrostomy present? If previous, removed how many months later? Tracheostomy present? If present, removed how many months later?
3. Details of UW-QOL HRQOL assessment
G. Current Status

1. Vital status (A=alive; D=dead); Current disease status (1=no evidence of head and neck cancer; 2=head and neck cancer present incl mets; 3=non-head and neck cancer; 4=immediately post treatment; 5=status unknown)
2. Date last known alive or date of death
3. Current follow up status (1=under follow-up; 2=lost to follow-up; 3=discharged; 4=last place of referral here)
4. Date gone abroad or interstate
APPENDIX M: DATASET FOR PATHOLOGIC REPORTING ATTACHMENTS

1 OF 5

DATASET FOR THE PATHOLOGIC REPORTING OF ORAL CANCER (ADAPTED FROM RCPA, STRUCTURED REPORTING PROTOCOL FOR ORAL CANCER, FIRST EDITION 2011)

Clinical information (for head and neck cancer at all sites)

- Patient name
- Date of birth
- Sex
- Identification and contact details of requesting doctor
- Date of request
- Ethnicity
- Pathology accession number
- Principal clinician involved in patient’s care
- Anatomic site
- Laterality of lesion: left, right, not stated
- Clinical history
- Human papilloma virus, HIV, Hepatitis B/C, TB status
- Clinical diagnosis or differential diagnosis
- Pre-operative
- Radiotherapy
- Chemotherapy
- Type of operation: incisional biopsy, excisional biopsy, hemi-glossectomy, partial glossectomy, hemimandibulectomy, segmental mandibulectomy, partial/hemi-maxillectomy, total maxillectomy, selective node dissection, modified radical neck dissection, radical neck dissection, extended radical neck dissection, wedge resection of lip
- Involvement of adjacent structures
- Distant metastases
Macroscopic findings

> Specimen: description, measurements __x__x__mm
> Mucosa: not received, received (dimensions __x__x__mm)
> Teeth: not received, received (number, type)
> Bone: not received, received (type, dimensions)
> Soft tissue: not received, received (description, dimensions)
> Salivary gland: not received, received (description, dimensions)
> Tumour
  > Size
  > Site
  > Appearance (polypoid, exophytic, endophytic, ulcerated, sessile, other)
  > Depth of invasion (mm)
> Surgical margins: distance to oriented margins in mm
> Involvement of adjacent structures: absent, present (bone, sublingual gland, submandibular gland, nose, sinus, teeth)
  > Neck dissection: Description and dimensions
  > Laterality (left, right)
  > Number and level of nodes (I, II, III, IV, V)
  > Gross extracapsular tumour extension (soft tissue, skeletal muscle, blood vessels, salivary gland)
  > Soft tissue surgical margin (involved, not involved (distance from tumour in mm)
> Distant metastases – absent, present

Microscopic findings

> Tumour type: squamous cell carcinoma, conventional
> Variants of squamous cell carcinoma: verrucous, basaloid, papillary, spindle cell, acantholytic, adenosquamous, undifferentiated, lymphoepithelial (non-nasopharyngeal)
> Carcinoma of minor salivary glands
  > Acinic cell carcinoma
  > Adenoid cystic carcinoma
  > Adenosarcoma, not otherwise specified (NOS) low grade, intermediate grade, high grade
  > Basal cell adenocarcinoma
  > Carcinoma ex pleomorphic adenoma
  > Carinosarcoma
  > Clear cell adenocarcinoma
  > Cystadenocarcinoma
  > Epithelial – myoepithelial carcinoma
  > Mucoepidermoid carcinoma (low grade, intermediate grade, high grade)
  > Mucinous (colloid) adenocarcinoma
  > Myoepithelial carcinoma
- Oncocytic carcinoma
- Polymorphous low grade adenocarcinoma
- Salivary duct carcinoma
  - Adenocarcinoma, non-salivary gland type
    - Adenocarcinoma NOS (low grade, intermediate grade, high grade)
  - Neuroendocrine carcinoma
    - Typical carcinoid tumour (well differentiated neuroendocrine carcinoma)
    - Atypical carcinoid tumour (moderately differentiated neuroendocrine carcinoma)
    - Small cell carcinoma (poorly differentiated neuroendocrine carcinoma)
    - Combined with non neuroendocrine elements
  - Mucosal malignant melanoma
    - Grade: well, moderate, poor
    - Tumour site
      - Tumour size: mm
      - Depth of invasion: mm
    - Growth pattern of invasion (I-V)
    - Inflammatory border reaction
    - Lymphovascular invasion: not identified, present
    - Perineural invasion: not identified, present (diameter of largest involved nerve)
  - Ulceration
    - Sialadenotropism: absent, present
    - Ductal involvement: absent, present
  - Bone invasion: absent, present (erosive, diffuse infiltration), margin involvement (no, yes)
  - Involvement of salivary gland: not involved, involved
  - Involvement of adjacent structures: absent, present (floor of mouth, skin of face, deep muscle of tongue, maxillary sinus, pterygoid plates, encases internal carotid artery, skull base)
  - Hypopharynx tumours: spread to larynx, oesophagus, thyroid/cricoid cartilage, hyoid bone, thyroid gland, central compartment soft tissue, prevertebral fascia, encases carotid artery, mediastinum)
  - Status of surgical margins (in situ, invasive, high grade dysplasia): not involved (distance from tumour to all oriented margins in mm), involved (specify margin and length of involvement)
  - Features suggestive of HPV association
    - Dysplasia/in situ carcinoma
    - Lymph nodes (total number of involved nodes/uninvolved nodes, levels)
    - Largest metastatic deposit __x__x__mm
    - Extracapsular tumour spread: absent, present (extent in mm)
    - Radiation/chemotherapy changes
> Additional Pathologic Findings
> Ancillary tests - Immunohistochemistry (p16, p53, Ki67), HPV, EBV, insitu hybridization, PCR, cytogenetics, other
> Pathologic Tumour Stage (AJCC) Year of publication and edition of cancer staging system
> Stage Grouping
> TNM Descriptors
2 OF 5: DATASET FOR THE PATHOLOGIC REPORTING OF LARYNX CANCER

Macroscopic findings

> Specimen
  - Larynx: supraglottis
  - Larynx: glottis
  - Larynx: subglottis
  - Other (specify)

> Procedure:
  - Incisional biopsy, Excisional biopsy, Resection
  - stripping (glottis)
  - transoral laser excision (glottis)
  - supraglottic laryngectomy
  - supracricoid laryngectomy
  - vertical hemilaryngectomy
  - partial laryngectomy
  - total laryngectomy

> Specimen size: Dimensions __x__x__mm

> Tumour
  - Size __x__x__mm
  - Laterality (right, left, bilateral, transglottic, midline)
  - Larynx: supraglottis (epiglottis, aryepiglottic folds, arytenoid, false vocal cord, ventricle)
  - Larynx glottis (true vocal cord, anterior commissure, posterior commissure)
  - Larynx subglottis
  - Focality (single, bilateral, multifocal)
  - Appearance (polypoid, exophytic, endophytic, ulcerated, sessile, other)
  - Depth of invasion (mm)

> Surgical margins: distance from tumour to oriented margins in mm

> Involvement of adjacent structures

> Neck dissection
  - Type (radical, modified radical, selective, extended)
  - Description
  - Laterality (left, right, bilateral)
  - Number and level of nodes (I, II, III, IV, V)
  - Gross extracapsular tumour extension (soft tissue, skeletal muscle, blood vessels, salivary gland)
  - Soft tissue surgical margin (involved, not involved), if latter distance from tumour in mm

> Distant metastases: absent, present
Microscopic findings

> **Tumour Type**: squamous cell carcinoma, conventional

> **SCC subtype**: acantholytic, adenosquamous, basaloid, papillary, spindle cell, verrucous, giant cells, lymphoepithelial carcinoma (non-nasopharyngeal)

> **Other**
  - Neuroendocrine carcinoma (typical carcinoid, atypical carcinoid, small cell carcinoma, mixed with non neuroendocrine components)
  - Mucosal malignant melanoma
  - Carcinoma of minor salivary glands (adenoid cystic, mucoepidermoid (grade) (other)

> **Grade**: well, moderate, poor

> **Tumour site**

> **Tumour size**: mm

> **Depth of invasion**: mm

> **Growth pattern of invasion**

> **Lymphovascular invasion**: not identified, present

> **Perineural invasion**: not identified, present

> **Local spread**: one cord, both cords, glottis, supraglottis, subglottis, mucosa base of tongue, vallecula, pyriform sinus, postcricoid, preepiglottic space, paraglottic space, thyroid cartilage, trachea, soft tissue of neck, strap muscles, deep extrinsic muscle of tongue, thyroid, oesophagus, prevertebral space, encases carotid artery, mediastinum

> **Status of surgical margins**
  - Invasive carcinoma
  - Not involved (distance from tumour to all oriented margins in mm)
  - Involved (specify margin and length of involvement)
  - Moderate and severe dysplasia (high grade SIN) or insitu carcinoma
  - no, yes at margins

> **Keratinizing/non keratinizing dysplasia** (mild, moderate, severe), in situ carcinoma -

> **Lymph nodes**
  - Total number of involved nodes/uninvolved nodes, levels, ipsilateral versus bilateral
  - Largest metastatic deposit __x__x__mm
  - Extracapsular tumour spread – absent, present (extent in mm)

> **Treatment effect** (**neoadjuvant therapy**): not identified, present, indeterminate

> **Additional pathologic findings**

> **Ancillary tests** - p16, HPV ISH, PCR

> **Pathologic Tumour Stage** (**AJCC**) Year of publication and edition of cancer staging system

> **Stage Grouping**

> **TNM Descriptors**
DATASET FOR THE PATHOLOGIC REPORTING OF SALIVARY GLAND CANCER

Macroscopic findings

> Specimen
  o Type (superficial, deep, total parotidectomy, submandibulectomy, sublingual gland)
  o Dimensions __x__x__mm

> Laterality: right, left, bilateral

> Tumour
  o Size __x__x__mm
  o Extraglandular extension (no, yes)
  o Multifocal (no, yes)
  o Appearance (colour, solid, cystic, haemorrhagic, necrotic, cartilaginous, translucent, encapsulated, invasive)
  o Duct involvement (no, yes)
  o Surgical margins: distance from tumour to oriented margins in mm
  o Involvement of adjacent structures: skin, bone, ear canal, carotid artery
  o Facial nerve involvement: no, yes
  o Lymph nodes: intraglandular/extraglandular, involved (no, yes)
  o Neck dissection: right, left, bilateral
  o Distant metastases: absent, present

Microscopic findings

> Tumour type: acinic cell carcinoma, mucoepidermoid carcinoma, adenoid cystic carcinoma, polymorphous low-grade carcinoma, epithelial-myoepithelial carcinoma, basal cell adenocarcinoma, sebaceous carcinoma, papillary cystadenocarcinoma, mucinous adenocarcinoma, clear cell adenocarcinoma, oncocytic carcinoma, salivary duct carcinoma, adenocarcinoma (NOS), myoepithelial carcinoma, carcinoma ex pleomorphic adenoma, squamous cell carcinoma, small cell carcinoma, lymphoepithelial carcinoma, low grade cribriform cystadenocarcinoma, carcinosarcoma, sialoblastoma

> Grade: (if applicable)

> Site: parotid, submandibular, sublingual, minor gland

> Tumour size (mm)

> Tumour focality: single focus, bilateral, multifocal

> Extraglandular extension: absent, present (periglandular soft tissue, skin, ear canal, encases carotid artery, bone (mandible, skull base, pterygoid plates))

> Lymphovascular invasion: not identified, identified

> Perineural invasion: not identified, identified
> Facial nerve involvement: no, yes

> Surgical margins: not involved (distance of tumour to closest margin in mm), involved (specify margin and extent of involvement)

> Non involved gland

> Lymph nodes: total number of involved nodes/uninvolved nodes, intraglandular versus extraglandular nodes, levels I-V

> Largest metastatic deposit: __x__x__mm

> Extracapsular tumour spread: absent, present (extent in mm)

> Soft tissue margin: involved, not involved (distance from tumour in mm)

> Treatment effect: not identified, present, indeterminate

> Ancillary tests:
  o Immunohistochemistry (myoepithelial markers, Ki67, Bcl-2, p53, Her-2, ER, PR, AR)
  o In situ hybridization, PCR
  o Cytogenetics
  o Electron microscopy

> Distant metastases: absent, present

> Pathologic Tumour Stage (AJCC) Year of publication and edition of cancer staging system

> Stage Grouping

> TNM Descriptors

> Residual Tumour (R)
DATASET FOR THE PATHOLOGIC REPORTING OF NASOPHARYNX CANCER

Macroscopic findings

- **Specimen**: Nasopharynx
- **Procedure**
  - Incisional biopsy
  - Excisional biopsy
  - Resection
- **Specimen size**: Dimensions __x__x__mm
- **Laterality** (left, right, bilateral, midline)
- **Focality** (single, bilateral, multifocal)
- **Tumour**
  - Size __x__x__mm
  - Appearance (polypoid, exophytic, endophytic, ulcerated, sessile, other)
  - Depth of invasion (mm)
- **Surgical margins** – distance from tumour to oriented margins in mm
- **Involvement of adjacent structures**
- **Neck dissection**
  - Type (radical, modified radical, selective, extended), description
  - Laterality (left, right)
  - Number and level of nodes (I, II, III, IV, V)
  - Gross extracapsular tumour extension (soft tissue, skeletal muscle, blood vessels, salivary gland)
  - Soft tissue surgical margin (involved, not involved), distance from tumour in mm
- **Distant metastases** absent, present

MICROSCOPIC FINDINGS

Tumour type

- Keratinising squamous cell carcinoma
- Non keratinising carcinoma
- Differentiated
- Undifferentiated
- Basaloid squamous cell carcinoma

Adenocarcinomas (non salivary gland type)

- nasopharyngeal papillary adenocarcinoma
- adenocarcinoma, not otherwise specified (NOS), (low grade, intermediate grade, high grade)

Carcinomas of minor salivary glands

- Acinic cell carcinoma
- Adenoid cystic carcinoma
- Adenocarcinoma, not otherwise specified (NOS) low grade, intermediate grade, high grade
- Basal cell adenocarcinoma
- Carcinoma ex pleomorphic adenoma
- Clear cell adenocarcinoma
- Cystadenocarcinoma
- Epithelial – myoepithelial carcinoma
- Mucopidermoid carcinoma (low grade, intermediate grade, high grade)
- Mucinous (colloid) adenocarcinoma
- Myoepithelial carcinoma
- Oncocytic carcinoma
- Polymorphous low grade adenocarcinoma
- Salivary duct carcinoma

**Neuroendocrine carcinoma**

- Typical carcinoid tumour (well differentiated neuroendocrine carcinoma)
- Atypical carcinoid tumour (moderately differentiated neuroendocrine carcinoma)
- Small cell carcinoma (poorly differentiated neuroendocrine carcinoma)
- Combined

- Mucosal melanoma

- Grade – well, moderate, poor, not applicable
- Tumour size – mm
- Depth of invasion – mm
- Lymphovascular invasion – not identified, present
- Perineural invasion – not identified, present

**Local spread**

- nasopharynx, extends to oropharynx, nasal cavity, parapharyngeal extension, bone invasion (skull base, sinuses), intracranial extension and/or involvement of cranial nerves, hypopharynx, orbit, infratemporal fossa/masticator space.

- Status of surgical margins (invasive carcinoma and insitu carcinoma/high grade dysplasia)
- Not involved (distance from tumour to all oriented margins in mm)
- Involved (specify margin and length of involvement)

**Lymph nodes**

- Total number of involved nodes/uninvolved nodes, levels I-VII, ipsilateral versus bilateral
- Largest metastatic deposit __x__x__mm
- Extracapsular tumour spread – absent, present (extent in mm)

**Treatment effect** (neoadjuvant therapy) – not identified, present, indeterminate

**Ancillary tests** – Immunohistochemistry, EBV-ISH

**Pathologic Tumour Stage (AJCC)** Year of publication and edition of cancer staging system
Stage Grouping

Residual Tumour (R)
DATASET FOR THE PATHOLOGIC REPORTING OF MUCOSAL MELANOMA OF THE HEAD AND NECK

Given this tumour's high risk of mortality, it is regarded separately from carcinoma of this region. Around two-thirds of tumours develop in the nasal cavity and sinuses, one quarter in the oral cavity and the rest rarely in other sites.

- **Site**
- **Tumour thickness (mm)**
- **Involvement of adjacent structures**: deep soft tissue, cartilage, bone, skin, carotid artery, masticator space, prevertebral space, lower cranial nerves (IX, X, XI, XII), skull base, dura, brain, mediastinum.
- **Ulceration**
- **Mitotic rate (per sq/mm)**
- **Lymphovascular invasion**
- **Perineural spread**
- **Margins**: not involved (distance from tumour to all oriented superficial and deep margins in mm), involved (specify margin and length of involvement). Record for both invasive and in situ melanoma.
- **Lymph nodes**:
  - **Total number of involved nodes/uninvolved nodes**, side, levels I-III, IV-V, VI-VII, other
  - **Largest metastatic deposit __x__x__mm**
- **Extracapsular tumour spread**: absent, present (extent in mm)
- **Pathologic Tumour Stage (AJCC)** Year of publication and edition of cancer staging system
  - *pT*
  - pN
  - pM
  - *Note primary melanoma limited to the mucosa is considered T3. Advanced melanomas are subdivided as moderately advanced T4a and very advanced T4b.*
- **Stage Grouping**
- **TNM Descriptors**
APPENDIX N: RECOMMENDED DATA INCLUSIONS FOR THE PATHOLOGIC REPORTING OF HEAD AND NECK CARCINOMAS

Primary tumour
- Tumour site
- Tumour type
- Maximum tumour diameter
- Tumour thickness (depth of invasion in mm)
- Pattern of infiltration
- Host lymphocytic response
- Lymphovascular permeation
- Perineural involvement
- Margins (invasive, in situ, moderate to severe (high grade) dysplasia)

Metastases
- Number of involved nodes
- Level of involved nodes
- Size of largest tumour mass
- Extracapsular spread
- Surgical soft tissue margin

Other prognostic factors:
- HPV ISH/ PCR p16, Ki67, p53
- *Pathologic Tumour Stage (AJCC), Year of Publication and edition of cancer staging system
  - pT
  - pN
  - pM

Stage Grouping
- TNM Descriptors
  - m (multiple primary tumours)
  - r (recurrent)
  - Y (post treatment)
- Residual Tumour (R)
  - RX cannot be assessed
  - R0 no residual tumour
  - R1 microscopic residual tumour
○ R2 macroscopic residual tumour
APPENDIX O: HEAD AND NECK CANCER
MULTIDISCIPLINARY TEAM TERMS OF REFERENCE

STATE-WIDE CLINICAL NETWORKS: HEAD AND NECK CANCER MDM TERMS OF REFERENCE

1. Definition of Multidisciplinary Care

Multidisciplinary care (MDC) is an integrated team approach to health care in which medical, nursing, and allied health care professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for each patient1

2. Aim

The overall aim of the multidisciplinary cancer meeting is to enable a formal mechanism for multidisciplinary input into treatment planning and ongoing management and care of patients with cancer.

The multidisciplinary team provides advice to the referring clinician. Treatment decisions are the responsibility of the primary clinician responsible for the patient.

3. Objectives of the MDM meeting are:

1. To ensure evidence-based treatment recommendations are being made with respect to patient management as clinical circumstances dictate.
2. To facilitate the referral, presentation and discussion of all new or recurrent head and neck cancer patients diagnosed in South Australia at the Multidisciplinary Team meeting.
3. To maintain documentation of treatment recommendations for each patient, and communicate these to relevant team members including the referring physician, primary physician, and patient's medical chart.
4. To provide an opportunity to discuss: enrolment of particular patients in clinical trials and research activities (including clinical audit).
5. To obtain data documenting time from initial patient presentation to diagnosis to treatment for each patient.
6. To provide an educational environment for multidisciplinary team members, fellows, registrars and interns and visiting clinicians.
7. To contribute to a complete database of head and neck cancers diagnosed in South Australia.

4. Operational Guidelines

4.1 Membership

1 NBOCC Multidisciplinary meetings for cancer care, a guide for Health Service Providers, National Breast Centre 2005.
Membership of the multidisciplinary cancer meeting comprises medical staff, nursing, allied health, pharmacy, psychosocial professionals, other supportive care services providing clinical services in relation to head and neck cancer throughout South Australia.

MDM Attendees:

The following categories of attendee have been ratified by the Cancer Clinical Network Steering Committee:

**Core clinical members:**

Medical consultants, medical registrars, RMOs, nurses and allied health clinicians for whom involvement/attendance at the MDM is a core part of their duties.

**Support staff:**

Staff members who may be required to assist with meeting implementation, for example administrative assistants.

**Invitees**

*Visitors:* clinicians such as GPs who are invited to attend the discussion of a particular patient.

*Observers:* such persons are included under the general patient agreement to be in attendance but are *non-contributory to the final decision. These include:*

- relevant health care profession students
- a clinician who is not a usual attendee and/or without direct connections with the hospital/service/MDM whose attendance is approved by the MDM Chair

**NB:** All MDM attendees are required to sign the attendance register and ensure the Chair is aware who is attending at remote sites.

Refer to Appendix B for a sample MDM meeting register.

**Credentialing Requirements:**

All core medical MDM members are required to be credentialed and scope of practice recognised in the health service where the MDM is located or centrally located in the instance where multiple sites are involved. This includes public and private medical staff. Core members who are primarily private practitioners, must, like public employees, be credentialed by a public hospital and have relevant scope of practice to attend the site at which the meeting is held.

It is the prospective/current MDM medical member’s responsibility to obtain health service credentials/mutual recognition of scope of practice to provide evidence to the MDM Chair for noting.

The Chair is responsible for ensuring core medical attendees are credentialed. The Chair may use discretion to allow that medical attendee to remain for the meeting.

Other non medical health professionals currently do not require credentialing for attendance at cancer MDM’s. Non-medical health professionals from the private sector are required to provide the Chair with evidence of professional registration for noting.

**Example of MDM Membership:**

Disciplines required for a head and neck cancer MDM include:
• Surgeons (3 or more designated surgeons who are likely to be OTHNS, Plastic and Reconstructive or Maxillofacial)
• Medical Oncologists (2;1 of which should always be present at Meetings.)
• Radiation Oncologist
• Special needs dentist
• Palliative Medicine Physician
• Radiologist +/- Nuclear Medicine Specialist with PET expertise
• Pathologist with expertise in both histopathology and cytopathology
• Clinical Nurse Specialist(s)
• Allied Health staff according to tumour type and patient need: e.g.
  • Dietitian
  • Speech pathologist
  • Physiotherapist
  • Social Work
  • Occupational Therapist
  • Senior nursing staff from ENT/Plastics/Head and Neck Clinic
  • Psycho-oncology services (Psychologist/Psychiatrist where appropriate)
  • Aboriginal Cancer Care Co-ordinator
  • MDM Co-ordinator
  • Other Supportive Care staff as required (e.g. addiction services, Audiology, pharmacist)

Relevant medical fellows / registrars / RMOs attached to a specialty will be members of the MDM team for the duration of their attachment.

Additional disciplines recommended for contributory involvement include:

• General Practitioner
• Neurosurgery, Ophthalmology,

Refer to Appendix B for a directory of team members for the Head and Neck Cancer MDM.

Those team members who are presenting a patient at the MDM are to arrange a proxy in the event that they are unable to attend the meeting.

When specific clinical needs have been identified by the referrers which require specific skills and targeted input the chairperson will invite the appropriate staff member(s) to attend that particular meeting.

4.2 Patients to be discussed

• All newly diagnosed patients
• Review patients either at relapse or with newly identified symptoms
• As requested by referring clinician in consultation with Chair
The referring clinician must send all referral details to the Chair/MDM Co-ordinator or Administrative Assistant (as agreed) no later than 2 days prior to the meeting. This is to facilitate prioritisation of presentations and to ensure adequate time for investigation results to be prepared for the meeting.

The referring clinician must ensure radiology is made available for the meeting, particularly private films. The administrative MDM support may be able to facilitate this when provided with relevant information to source radiology images/pathology.

Consent
All patients must be made aware that their case will be presented at the multidisciplinary team meeting for discussion and consent to this process. Consent may be either verbal or written and it must be noted in the patient's clinical health record and/or on the multidisciplinary meeting referral form.

(Patient information brochure on multidisciplinary team meetings is available)

4.3 Chair
Good leadership and facilitation are key factors in the success of multidisciplinary team meetings.

Role of the Chair²
- Keeping meetings to the agenda
- Ensuring all visiting members are appropriate to the meeting and where required exclude attendees
- Ensuring there is appropriate representation in the meeting to enable a comprehensive recommendation to be made
- Commencing and facilitating discussions
- Prompting the full range of input into discussions if it is not forthcoming
- Summarising the discussion and inviting further input before moving to the next case
- Negotiating resolution of conflict
- Promoting mutual professional respect among all team members.

The Chair and Deputy Chair positions will be appointed annually. If the Chair or Deputy Chair is unable to attend, the Chair will arrange a proxy to chair the meeting.

4.4 Meeting Time & Venue
Meetings should be held at the same time and place. The duration and frequency of meetings will be determined by each MDM meeting based upon size of site/number of cases requiring discussion.¹

² NBOCC Multidisciplinary meetings for cancer care, A guide for Health Service Providers, National Breast Centre 2005.
The day and time of meetings should be convenient for core members who should also be asked to submit best times to ensure a mutually beneficial time for all attendees and due consideration for off site members including rural. It is appropriate to limit the meetings to 45 – 90 minutes. Any time not used for case discussion may be used for educational purposes or discussion of other relevant issues. Meeting room facility must meet the requirements of the MDM (i.e. access and display of radiology images, pathology slides, videoconferencing etc).

4.5 Meeting Agenda

Case presentation will be determined and prioritised by the Chair upon review of referrals and/or discussion with referee.

The Chair will determine closing day/time to receive referrals. All late referrals must be discussed with the Chair. (It is suggested at least 2 days prior to the meeting to be the closing day of referrals to enable MDM coordinator/administrative support to ensure required patient information is available at the meeting)

The Agenda will include:

- Meeting Particulars
- Information required for patient presentation:
  - Patient’s name, DOB, UR no.
  - referring Clinician
  - comprehensive clinical summary including psychosocial factors
  - test results
- Education topic
- Other business

The referring clinician must provide the MDM Chair with the appropriate clinical summary and investigation/diagnostic test results prior to the MDM Meeting.

Late inclusions to the agenda are acceptable. In this instance it is the responsibility of the presenting clinician to ensure all appropriate clinical results are available to the meeting.

The Agenda will be circulated 2 days prior to the meeting. Hard copies may be provided at the meeting.

The MDM Chair will provide the team with a summary of outcomes from the previous meeting.

In the absence of adequate numbers of patients to discuss the MDM Chair or delegate will arrange an education session for the team.

4.6 Case Discussion

Only patients whose referring clinician (or their delegate) is present at the meeting will be discussed.

The referring clinician is responsible to ensure that all necessary patient clinical information is available for the meeting.

Case presentation and discussion will include the patient’s clinical condition and any relevant psychosocial aspects impacting on clinical management.

The Chair will summarise the recommendations made from the discussion before moving to the next case.
The Chair will provide a summary for all cases discussed during the MDM. A copy of the summary and treatment recommendation will be distributed to the referring clinician who will subsequently notify the patient and patient’s GP, other relevant MDM members, and the original copy will be filed into the patient’s medical record.

4.7 Confidentiality

All patient information presented remains confidential and only to be used for the purpose of clinical management.

All health care professionals are subject to confidentiality agreements through their regular employment.

4.8 Education

Multidisciplinary team meetings provide opportunities for sharing of expertise, enhancing understanding of the diversity of provider roles and dissemination of information to enhance best practice in provision of cancer care.

This can be achieved by:

- Multidisciplinary case presentations and care planning
- Participation by all providers
- Scheduling of regular presentations by team participants as a forum for
  - providing feedback from conferences,
  - disseminating current information relevant to specific tumour cancer care
  - education specific to provider specialties.

4.9 Meeting Documentation

Referral documentation records will be kept by the Chair/MDM coordinator/MDM administrative support. A record of the referral is required to be filed into the patient clinical health record.

Treatment and management recommendations from the meeting discussion will be documented on the MDM recommendation proforma which must be made available to the referring clinician and inserted in the patients’ clinical health record. The Chair signature is required.

The referring clinician or delegate is responsible for discussing the meeting recommendations with the patient/family/carer within 3 days and developing the treatment plan which takes into account the patient preferences. This plan is to be made available to relevant team members, the GP and noted in the patient’s clinical health record.

The MDM Chair will maintain one copy of the agenda and all attendance records.

4.10 Performance monitoring

MDM Key performance indicators should be regularly reviewed. These may include:

- Number of patients discussed
- Number of patients reviewed
- Service origin of patients discussed
- Number of attendees
- Differentiation of providers attending
- Number of education sessions
It is recommended that the MDM database is used to aid standardised data collection and to aid running of reports for review by the team.

An ongoing review of satisfaction and effectiveness will be conducted informally 6 monthly.

Formal evaluation will be conducted annually and results communicated to the MDM members for action as required.

**Adoption of Terms of Reference**

All members of the MDM will be provided with the terms of reference.

The MDM Chair is responsible for ensuring members adhere to the MDM terms of reference.

MDM members are responsible for adhering to the terms of reference.

The terms of reference require review every two years and when/if core member’s change.

**Subsequent revision dates:**

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APPENDIX P: DETAIL ON TREATMENT MODALITIES

Chemotherapy

Definitive chemoradiotherapy

External beam radiation combined with chemotherapy can be used with curative intent in patients with locoregionally advanced head and neck cancer who are deemed medically unfit for surgery or where surgery is deemed unnecessarily morbid or where the patient declines surgery. It is also used where organ preservation is the preferred option.

In a randomised phase III trial (The Head and Neck Intergroup) to test the benefit of adding chemotherapy to radiation in patients with unresectable squamous cell carcinomas of the head and neck there was a 7% improvement in median survival.\textsuperscript{108} This trial also highlighted the need for careful selection of patients as there was increased morbidity associated with the combined modality arm. Other trials in laryngeal cancer and nasopharyngeal cancer\textsuperscript{109} also showed improved survival where cisplatin was added concurrently to the radiation. Other trials assessing patients with oropharyngeal cancers\textsuperscript{110,111} also showed improved survival where cisplatin was added concurrently to the radiation. Other trials assessing patients with oropharyngeal cancers showed a similar magnitude of benefit\textsuperscript{110,111}. This constitutes category 1 evidence for the use of single agent cisplatin in this setting. There are minimal or lower levels of evidence for combination single agent carboplatin chemotherapy with radiotherapy. Single agent carboplatin and cisplatin have not been directly compared. The strongest evidence exists for high dose single agent cisplatin 100mg/m\textsuperscript{2} given every 21 days for 2 to 3 cycles. Weekly cisplatin 40mg/m\textsuperscript{2} can be given for the duration of the radiation where it is deemed the patient’s coexisting morbidities may make a single large dose hazardous. The evidence for weekly cisplatin is less substantial than for three weekly.

Targeted therapies

An alternative to concurrent chemotherapy is the use of a targeted treatment with the monoclonal antibody cetuximab. Cetuximab is a monoclonal antibody against the epidermal growth factor receptor. The epidermal growth factor receptor (EGFR) is abnormally activated in head and neck cancers, most of these cancers having high levels of EGFR. The evidence supporting the use of Cetuximab combined with radiation comes from a phase III randomised trial\textsuperscript{112}. The Cetuximab commenced one week prior to radiation and continued weekly for the duration of radiation. There was a 10 month improvement in locoregional control in the combined treatment arm (24 months versus 14 months) versus the radiation arm alone. The median duration of overall survival was also improved by 20 months for the combined arm (49 months versus 29 months). Cetuximab added to radiation also results in increased toxicity compared with radiotherapy alone. Chemoradiotherapy has not been directly compared to cetuximab-radiotherapy but the magnitude of the benefit with either appears to be similar.

The toxicity profile of cisplatin differs to that of cetuximab. Cisplatin is associated with significant nausea and vomiting, renal impairment, mucositis, hearing loss, peripheral neuropathy and febrile neutropenia. Cetuximab toxicity can result in mucositis, diarrhoea, acreniform rash, hypersensitivity reaction, hypomagnesaemia, hypokalaemia, hypocalcaemia. The choice of cisplatin or cetuximab is based on the patient’s comorbidities and general fitness to tolerate chemotherapy. Cetuximab is commonly considered as an alternative to cisplatin chemotherapy in the elderly and frail. However, it should be cautioned that in the Bonner trial the median age of patients was 56 years and the trial did not specifically evaluate elderly patients or those of poor performance status. Cetuximab has category 1 level of evidence for its use.

Ongoing trials are investigating the use of chemotherapy together with cetuximab and radiation. This should not be considered appropriate treatment outside a clinical trial.
**Induction (neoadjuvant) chemotherapy**

Induction or neoadjuvant chemotherapy refers to chemotherapy given prior to definitive surgery or chemoradiotherapy. It aims to downsize the tumour prior to definitive treatment and at the same time has been shown to reduce the rate of distant metastases. The use of induction chemotherapy remains an area of controversy among head and neck oncologists. Most randomized trials of induction chemotherapy followed by radiotherapy or surgery, published in the 1980s and 1990s, did not demonstrate a survival advantage. Induction chemotherapy had no effect on local control but reduced the distant metastases rate. Results from 3 phase III trials comparing cisplatin/5fluorouracil with or without the addition of a taxane- followed by the same locoregional treatment- showed significantly better outcomes (Response rates, disease-free survival and overall survival depending on the trial) for patients in the triplet group compared to the doublet. However, a survival advantage from the addition of induction chemotherapy to concurrent chemoradiotherapy has yet to be demonstrated with the exception of hypopharyngeal cancer for which there is category 1 evidence.\(^\text{113}\)

In conclusion induction chemotherapy should be considered a valid option for advanced hypopharynx tumours, for patients in the setting of a clinical trial or where the multidisciplinary team considers it imperative for the patient to begin some treatment whilst awaiting definitive surgery or chemoradiotherapy. Toxicity with induction chemotherapy using taxotere, cisplatin and 5 fluorouracil (TPF) is quite significant. It is associated with significant risk of febrile neutropenia, renal toxicity and neurological toxicity. It is generally considered difficult to follow TPF induction chemotherapy with concurrent cisplatin and radiotherapy. Most centres use weekly carboplatin or cetuximab with the radiotherapy.

**Postoperative chemoradiotherapy for patients with high risk disease**

The role of chemotherapy in the post-operative management of the patient with adverse prognostic risk factors is based on 2 large phase III trials both published in 2004, showing an 8-12% improvement in loco-regional and disease free survival. The 2 trials differed slightly in what was deemed as high risk factors. In common they both included patients with positive surgical margins or extracapsular nodal spread of tumour. The RTOG trial demonstrated improved locoregional control and disease-free survival with post-operative concurrent chemoradiotherapy. The EORTC trial\(^\text{114}\) also demonstrated an improved overall survival. Both trials used a three weekly cisplatin regime. The presence of other adverse risk factors-multiple positive nodes (without extracapsular spread), vascular/lymphatic/perineural invasion, pT3 or pT4 primary, and oral cavity or oropharynx primary cancers with positive level 4 or 5 nodes were also considered indications for postoperative concurrent chemoradiotherapy but the evidence is less strong.

A third trial by Fietkau,\(^\text{115}\) the German ARO 96-3 differed from the previous 2 trials by having differing doses of radiotherapy with or without chemotherapy which was cisplatin and 5FU. It also showed improved disease free survival and locoregional control rate. A metaanalysis of postoperative chemotherapy trials in head and neck cancer was published in 2000\(^\text{116}\) and updated in 2009\(^\text{117}\) using individual patient data. It confirmed an overall survival benefit of 4.5% at 5 years (31.1% vs. 35.6%) for patients who received chemotherapy as well as radiotherapy regardless of the timing of chemotherapy. In patients who had concomitant chemotherapy and radiotherapy there was a 6.5% overall survival benefit at 5 years.

As with definitive chemoradiotherapy cetuximab can be substituted for the cisplatin although the evidence here is extrapolated from the definitive radiotherapy cetuximab trials.
**Palliative chemotherapy**

This is treatment given when there is no possibility of surgical resection of the locoregional disease and curative radiotherapy options have been exhausted or where the patient has metastatic disease. The goal for such patients is palliation of symptoms or prolongation of survival. All patients considered for palliative chemotherapy should have a performance status of 0 to 2 as all the potential treatments can have significant toxicities. Patients should be fully informed about the goals of treatment, cost of combination chemotherapy, and potential for added toxicity.

It is possible to give palliative chemotherapy with radiotherapy on certain occasions. However, in most instances chemotherapy is used alone. Participation in clinical trials is preferred for all patients where available.

A variety of chemotherapy agents have been used for metastatic disease. Single agents and combination systemic chemotherapy regimens have both been used. In general the combination regimens result in higher response rates, greater toxicity and no improvement in survival compared with single agents. Response rates to single agents range from 15 to 35%. The most active agents are cisplatin, carboplatin, paclitaxel, docetaxel, 5-Fluorouracil, methotrexate and cetuximab. Funding is at present unavailable in Australia for the taxanes or cetuximab. Combination regimens result in response rates of 30 to 40%. The median survival with chemotherapy is approximately 6 months, and the 1 year survival rate 20%. The most active combination regimen was reported in the EXTREME phase III randomized trial. It found patients with recurrent or metastatic SCC had an improved median survival when they received Cetuximab plus cisplatin/5FU or carboplatin/5FU compared to the standard chemotherapy doublet (10.1 months versus 7.4 months p= .04). Toxicity was similar between arms. This combination is considered the gold standard worldwide but can be used in Australia at present only if the patient funds the Cetuximab and the cost is substantial.

**Toxicities associated with chemotherapy**

In general the acute toxicities of radiotherapy are exacerbated by concurrent chemotherapy. Patients having concurrent treatment usually experience more mucositis tend to have greater weight loss and more frequently require a feeding tube during treatment. The duration of acute toxicity tends to be longer with concurrent treatment.

Chemotherapy-specific toxicities are nausea and vomiting, neuropathy, nephropathy and ototoxicity. Addition of chemotherapy to radiotherapy can cause significant anaemia, leucopenia and neutropenia along with febrile neutropenia. Dose reductions are commonly needed. Complication rates are increased with more advanced intercurrent conditions. In elderly patients the presence of comorbidities has a definite impact on survival.
Radiotherapy

**Conventional Fractionation**

The most common conventional fractionation schedule is 1.8-2 Gray (Gy) in a single fraction per day, five days a week, for seven weeks. Tumours of the head and neck are in close proximity to structures such as the spinal cord, brain stem, parotid glands, and optic pathway structures; all radiotherapy requires an allowance for uncertainties in tumour definition. The margin required for adequate tumour coverage will involve treating healthy tissue to a full of dose radiation and hence side effects of treatment.

**Altered Radiation Fractionation**

While radiotherapy is the primary treatment modality for advanced disease, moderately accelerated schedules (six fractions/week) or Hyperfractionated schedules with increased total dose is considered for patients who are unable to receive concurrent chemotherapy.

During accelerated fractionation, the rate of dose exceeds 10Gy per week, resulting in a reduction in overall treatment times. Hyperfractionation is a modified fractionation schedule where the total dose is delivered in an increased number of fractions, and fraction size is below the conventional level of 1.8-2Gy². Altered fractionation with concomitant boost or hyperfractionation for stage III or IV may be considered as an option for standard therapy for oral cavity, oropharynx, supraglottic larynx, and hypopharyngeal squamous cell cancers (RTOG Protocol 90-03).

A 2010 Cochrane review concluded altered fractionated radiotherapy showed significant improvement in locoregional control, but no significant improvement in two year overall survival in patients with head and neck squamous cell carcinoma. The question of whether using altered fractionation as part of concurrent chemoradiotherapy will improve outcomes (without adding acute toxicities) is still awaiting evidence from current trials.

**Intensity-modulated Radiation Therapy (IMRT)**

IMRT produces a three dimensional dose distribution based on multiple external beams that can more accurately wrap around curved structures than 3D conformal radiotherapy. The main advantage of IMRT is that it avoids excessive radiation of normal tissues adjacent to the tumour allowing higher radiation doses applied to the tumour volume. There is evidence of improvements in local tumour control, and marked reduction of xerostomia, and a minimized risk for radio-osteonecrosis following IMRT.

Clinical trials for the use of IMRT are still limited to the prevention of xerostomia, but there are still established strong institutional and patient preferences for the use of IMRT. Therefore the therapeutic impact of IMRT on tumour control and patient survival still requires further randomized multi-centre trials before there is standard practice.

**Prevention and management of Radiation Side Effects**

The effects of radiotherapy on normal tissue are generally categorized as acute and late radiation damage. Acute radiation damage includes side effects that occur during radiotherapy, or the first 3 months following radiotherapy. Acute toxicity is usually transient and affects rapidly proliferating tissue, such as mucosa; resulting in mucositis.

Late radiation damage is often permanent, and can occur months or many years after radiotherapy (by definition, all damage to normal tissue that occurs or persists more than 3 months after the end of radiotherapy is considered late damage), and can result in significant alteration in the patient’s quality of life.

The effects of radiotherapy on the tumour and surrounding normal tissue is dependent on
The total dose administered
The size of each fraction
The overall time in which the total dose is delivered
Patient related factors, such as co-morbidities (diabetes mellitus) and smoking status

Radiation damage to surrounding tissues, and particularly late effects should be graded and recorded as completely as possible. Grading according to the American NCI Common Toxicity Criteria (CTC) was developed for both acute and late radiation damaged; generally grade 0 is no damage, and grade 3 or higher is considered severe radiation damage. The system was completely updated recently (CTEP CTC-AE = cancer therapy evaluation programme common toxicity criteria-adverse events) in order to prompt accurate reporting of radiation side effects, and correlate objective radiation side effects with dosimetric factors.

**Postoperative Radiotherapy**

Postoperative radiotherapy is indicated for patients with a high risk of locoregional recurrence. This includes:
- High risk: narrow or positive margins with T1, T2 disease, extranodal growth in one lymph node. Recurrent disease after previous radical surgery.
- Very high risk; extranodal growth in two or more lymph nodes, narrow radical or non-radical resection of T3 disease, N3 disease T4 disease.

Level 2 evidence has demonstrated that the interval between surgery and the start of radiotherapy as well as the overall treatment time of radiotherapy is relevant, i.e. the total treatment time calculated from the start of surgery to the end of radiotherapy should be kept as short as possible.

**Chemoradiotherapy**

Concomitant chemoradiotherapy (CCRT) is considered the established standard for non-surgical management of locally advanced (stage 3 and 4) head and neck cancers. For patients with head and neck cancer with positive resection margins (<1 mm) and/or extranodal growth, postoperative chemoradiation is significantly more effective than postoperative radiotherapy (8-12% improvement in locoregional control and disease-free survival). [Level 1]

The increased use of non-surgical organ preservation therapies, such as alternative fractionation and chemoradiation, improves locoregional control and often survival. Unfortunately, functional preservation is not always achieved, as dependence on a feeding tube occurs in 25% of patients treated with chemoradiation. The use of chemoradiation for resectable tumours with the goal of organ preservation and quality of life are playing an increasingly important role in multidisciplinary discussions.
Plastic and reconstructive surgery

The options for reconstruction following upper aerodigestive tract tumour excision are dependent on the site of the tumour, the size of defect and the prognosis of restoration of function. The decision is patient-centred and the patient’s ability to withstand and rehabilitate from a potentially lengthy procedure in their medical and social context is taken into account.

If the tumour, and therefore the resultant defect is likely to be small, then the defect may be closed directly. As defects get larger then function and cosmesis may be restored with local flaps such as buccinator, facial artery musculomucosal or tongue flaps. Larger defects of the pharynx may be sealed with pectoralis major flaps, turned about their blood supply into the defect. This type of reconstruction is usually performed in individuals as a salvage procedure or patients who cannot withstand a prolonged operation as in a free flap.

Cosmesis and function may be improved with free microvascular autologous tissue transfer, i.e. the use of tissue from a distant site that is anastomosed into local vessels using microsurgery in order to establish its own blood supply and heal, (free flap). Each flap is selected based on its constituent tissues’ ability to meet the functional and cosmetic requirements of the defect. Examples of such transfers include:

- Free radial forearm fasciocutaneous flap: oropharyngeal, partial/total laryngectomy, hemi/total glossectomy, floor of mouth defects
- Rectus abdominis muscle/muculocutaneous flap: maxillectomy, base of skull/lateral temporal bone excision
- Anterolateral thigh flap: lateral temporal bone excision, total laryngopharyngectomy
- Fibula osseocutaneous flap: Mandibulectomy, superior alveolus as part of maxillectomy
- Deep circumflex iliac artery (DCIA) flap: mandibulectomy, superior alveolus as part of maxillectomy, orbital floor

Each of these reconstructions has its own indications, contraindications and challenges and therefore they are not directly prescriptive in nature.

If the facial nerve is anticipated to be excised as part of the extirpative procedure, then a plastic surgeon can offer facial reanimation procedures to reduce the morbidity of this (lagophthalmos, exposure keratoconjunctivitis, facial asymmetry, lack of smile), either at the same operation or at a later stage.

Therefore a plastic and reconstructive surgeon with a specialist interest in head and neck reconstruction should be present at the MDM to advise on suitable options and outcomes and help to formulate a surgical plan. The patient should be seen by the reconstructive surgeon prior to the operation to discuss issues surrounding the reconstruction.

Each patient who undergoes a reconstructive procedure by a plastic surgical team will be managed as an inpatient by that team to ensure the optimum monitoring, identification of any need for intervention where necessary, and care is provided to support the patient and their reconstruction during their stay.

In addition to the recommended follow-up monitoring for cancer surveillance, every patient who undergoes a reconstructive procedure should be followed up by the plastic surgical team to assess the integrity and function of the reconstruction and to identify any need for intervention as further revisional surgery or allied medical input (speech pathology, occupational therapy, physiotherapy); and to audit the outcomes of the procedures being performed. Several such outpatient appointments may be required as some of the outcomes may evolve over years.
APPENDIX Q: GUIDELINES FOR THE TREATMENT OF SPECIFIC TUMOUR TYPES

ORAL SQUAMOUS CELL CARCINOMA

Decision Making

The management of oral carcinoma is primarily by surgical resection, with management of the neck lymph nodes as appropriate to the primary tumour characteristics and the clinical and radiologic staging of the neck.

The primary reason for this is that the majority of oral tumours relate to an exposure of the entire oral epithelium to the aetologic agents causing cancer (cigarettes, alcohol) and the tendency to multiple synchronous or metachronous lesions is high. As a result, accurate mapping and resection of a primary tumour allows more accurate treatment of the affected tumour volume than radiotherapy. The tendency to cause generalised mucositis in patients who already have dysplastic changes in their oral epithelium causes marked impact on functional outcomes. In particular, dryness of the mouth following radiotherapy causes an accumulative functional impairment of a patient, already affected by the impact of the primary tumour.

The secondary reason for surgery being the main treatment option is that it gives an accurate prognostic measure of the outcomes of the tumour, and the need for neck dissection in those with high risk tumours, or adjuvant radiotherapy in those with high risk tumours. Thus treatment can be stratified to deliver care as appropriate to the individual with best oncologic safety and least functional impairment.

Treatment options

In general, all patients will be offered surgery to the primary site. Those who are clinically and radiologically negative for neck lymph node metastases will be offered a selective neck dissection if the risk of microscopic neck metastases is high, as judged by the clinical, radiologic and histopathologic assessment of the primary tumour. In these patients, the use of adjuvant radiotherapy +/- chemotherapy will then be assessed, based upon the histological findings of the primary site and the neck.

Those patients who are clinically, radiologically and / or cytopathologically positive for neck nodal disease, will be offered resection of the primary site and the draining neck nodes, as a modified radical neck dissection. Again, the use of adjuvant radiotherapy +/- chemotherapy will then be assessed, based upon the histological findings of the primary site and the neck.

The place for primary radiotherapy is offered to those patients deemed unfit to undergo any surgical procedure, where the risk to life from surgical treatment outweighs the risk from the cancer. This will involve holistic assessment of the patient in a High Risk Clinic by Surgeons, Physicians and Anaesthetists.

Careful assessment of the mental and psychological ability of these patients to consent to any therapy should be undertaken, involving the patient, family, other supporting individuals, general practitioners and possibly specialist Psychiatric or Psychology services. Following this, the patient may then opt for radiotherapy treatment, having understood their decision and outcomes - both oncologic and functional.

In patients primarily treated by surgery in which there is local and / or regional recurrence, reassessment via the Multidisciplinary Clinic of the clinical and radiologic extent of recurrence is assessed and a plan for salvage discussed. This may include surgical treatment and / or radiotherapy (if not used previously).

In patients who have been previously treated with radiotherapy, who develop local and / or regional
recurrence, the MDM discussion will probably advocate surgical salvage where appropriate.

In those in whom recurrence is deemed to be too extensive to salvage, or spread to distant sites, or in those in whom the risk of treatment is hazardous to the health of the patient, palliative care will be offered. This may be palliative surgery, radiotherapy, chemotherapy or supportive care alone.

**Trans-oral surgery technique descriptions and reconstruction**

The surgical approach to the primary tumour depends upon clinical and radiologic staging including panendoscopy and an understanding of the pathways of tumour spread and each tumour's inherent biology.

The approach chosen is also affected by the plan.

Tumours of the upper jaw and hard palate, extending into the maxilla and ed management of the neck and plan for reconstructive surgery, if required.

Within this, most oral tumours can be resected via a transoral approach alone, using retraction of lips, tongue and soft tissue for access. Tumours with extension into the mandible may require segmental resection of the mandible with the primary tumour. Extension to the extrinsic muscle of the tongue or into the neck may require a resection of soft tissue from the oral cavity into the neck, combining this with a neck dissection.

The need to split the lip and / or the jaw simply for access is now a rare event, as most cancers can either be accessed by direct transoral resection, by visor approach with elevation of the soft tissue of the lip and jaw, or via lingual release, with delivery of the tongue and oral structures into the neck. These options allow access to the entire oral cavity and jaw for resection and reconstruction in most cases. nasal cavity may require sublabial degloving to access the anterior facial skeleton, or a lateral rhinotomy approach.

Tumours of the posterior oral cavity extending into the oropharynx may be best approached using a transoral robotic approach, allowing rigid endoscopies and stereoscopic visualisation of the tumour and accurate resection, without the need to split the mandible or deliver the tongue into the neck.

The requirement for reconstruction is based upon the site and extent of the primary tumour and the functional results associated with the reconstructive option. In general oral cancers can be reconstructed by primary closure of the defect, leaving the defect to heal by secondary intention, the use of split skin grafts, local flaps, regional flaps and free flaps. The use of free flaps may be as skin alone, skin and soft tissue or skin, soft tissue and bone, as required by the functional outcome needed following primary tumour resection. Choice of reconstructive techniques should be made on an individual basis, according to anatomical location of tumour, general condition of patient, patient's preference and surgeon’s preference.

**Metastatic neck disease considerations**

The need for neck nodal dissection in oral cancer is predicated upon the clinical, radiologic and histological features of the primary tumour and the draining lymph nodes in the neck.

In general, patients who are clinically and radiologically neck negative and are judged from the histological parameters of the primary tumour to have a low risk for metastatic spread to the neck may be closely observed with clinical and radiologic imaging.

Those patients who are neck negative and have a high risk of microscopic neck nodal spread are offered a selective neck dissection, with the regions dissected dependant upon the likely pathways of metastatic dispersal of the primary tumour. Often this will involve dissection of levels I-IV, for instance.
Those patients who are clinically, radiologically and/or cytopathologically positive for neck nodal spread will be offered an ipsilateral modified radical neck dissection as a minimum, with possibility of a contralateral selective neck dissection if the risks of tumour spread are high, dependant on the extent of nodal spread on the ipsilateral side and the site and extent of the primary tumour.

Airway management

The post-operative management of the airway is usually planned prior to surgery. As a generality, patients may be extubated on the operative table, and breathe spontaneously transorally/transnasally in cases of small volume resection without risk of acute or delayed swelling affecting the stability of the airway.

Those patients with extensive tumour resection involving the primary site, neck and in those with flap reconstruction (free or regional) may be planned for a temporary tracheostomy to allow stable delivery of oxygen without risk of airway compromise in the first few days after surgery.

Those patients in whom the risk to the airway seems temporary and mild may remain intubated postoperatively for 24-48 hours and then decannulated in ICU or HDU once they are judged to have a safe and stable airway. A small number of these patients may fail to be decannulated and may require an emergent tracheostomy as a temporary measure until swelling has settled and a stable airway is achieved.

Advice and support from Speech Pathologists, Dietitians, and early Dental assessment by Special Needs Dentists are also important considerations of treatment.

OROPHARYNGEAL SQUAMOUS CELL CARCINOMA


HYPOPHARYNGEAL SQUAMOUS CELL CARCINOMA

Anatomically the hypopharynx can be divided into three subtypes: pyriform sinus, posterior pharyngeal wall, and postcricoid area; hypopharyngeal cancer most commonly affects the pyriform fossa (sinus). Smoking or chewing tobacco and excessive alcohol consumption are known risk factors, but HPV as a direct cause of hypopharyngeal cancer is uncommon, unlike oropharyngeal SCC.

Unlike laryngeal cancer, up to 80% of hypopharyngeal cancers present at an advanced stage III or IV, since they can be asymptomatic until they are quite advanced. 50% present because of cervical nodes and incidence of distant metastasis at presentation. Nodal involvement, like all head and neck cancer, halves the prognosis. Therefore USgFNAC and cross-sectional imaging (CT or MRI) is part of the workup, along with a thorough history (including dysphagia, referred otalgia, hoarseness and aspiration), examination and panendoscopy with biopsies. PET-CT is most accurate, and particularly accounts for distant metastases.

Due partly to the strong associations with alcohol and late presentation, and the complex nature of the management of hypopharyngeal cancer, consensus MDM opinion is sought and treatment individualised to the patient with counselling.

Treatment

Early (stage I-II) hypopharyngeal cancer is treated by either surgery or radiotherapy. Surgery may be either open partial pharyngectomy or endoscopic laser resection, but a selective neck dissection is strongly recommended.
Advanced (stage III or IV) hypopharyngeal cancer is treated by surgery with adjuvant (postoperative radiotherapy +/- chemotherapy) or primary chemoradiotherapy +/- salvage surgery.

The priority in management of this group is primarily cure, though functional preservation plays a big role in decision making for patients. Because the risk of occult lymph node metastases is present in 30-40% of patients, any treatment plan should include elective treatment by bilateral cervical lymph node dissection or post-operative irradiation. The other issue, like laryngeal cancer, is subsite involvement. Postcricoid cancer is not amenable to conservative surgery.

Hypopharyngeal cancers overall have a high propensity to submucosal spread, and to a much higher long term gastrostomy and tracheostomy dependence than other head and neck cancers. So while ‘organ sparing therapy’ may be attractive, patients should be counselled about long term adverse effects on swallowing, breathing and speech by experienced Speech Pathologists.

Early (T1N0 and T2N0) hypopharyngeal cancers

Local control can be achieved by treating patients with definitive radiotherapy alone or by surgery alone (with radiotherapy available for adjuvant treatment if pathology indicates poorer prognostic features). Surgery options include endoscopic laser resection, open partial pharyngectomy +/- partial laryngectomy, or total laryngectomy with partial or total pharyngectomy and selective neck dissections as per levels above. Postcricoid lesions are not amenable to partial surgery, and medical pyriform sinus lesions need careful assessment.

Advanced hypopharyngeal tumours

Options here are either radical surgery with adjuvant radiotherapy or primary chemoradiotherapy +/- salvage surgery.

Surgery consists of total laryngopharyngectomy or total laryngectomy with partial pharyngectomy, with neck dissections as appropriate. For involved neck nodes, either a modified or radical neck dissection is standard, otherwise a selective neck dissection for prophylactic and staging purposes. (The only exception to radical surgery being posterior pharyngeal wall tumours that may be amenable to a partial pharyngectomy with neck dissections and adjuvant radiotherapy).

Reconstruction is performed primarily with pedicled or free vascularised grafts. Increasing evidence suggests improved overall survival and locoregional control with inclusion of chemotherapy with radiotherapy postoperatively.

For advanced neck disease, neck dissection followed by chemoradiation for the primary is an option. For patients with T4 tumours and extensive involvement of cartilage and/or soft tissue, the preferred approach is total laryngopharyngectomy or total laryngectomy with partial pharyngectomy and bilateral neck dissections followed by postoperative radiotherapy or chemoradiation. The goal is to achieve the shortest possible interval between surgery and the start of radiotherapy or chemoradiation, preferably within six weeks.

Unresectable tumours or palliative situations

For patients with unresectable disease, either concurrent chemoradiation can be considered with the hope of cure, or with palliative intent. Palliative radiotherapy in isolation for those unsuitable for chemotherapy can be given. Decision must be made regarding the intent of treatment (cure, hope of cure, or palliation). The other options in palliative situations that must be considered are tracheostomy, feeding tubes, or simply best supportive care with no intervention. Clear decisions must be made with the patient, carers and specialists, including palliative care, regarding treatment or not of aspiration pneumonia and bleeding.
LARYNGEAL SQUAMOUS CELL CARCINOMA

Decision Making

The management of laryngeal carcinoma requires (1) quantifying and cessation of risk factors, particularly smoking, (2) localization of the primary region (glottis, supraglottis or subglottis), (3) proper staging, (4) histologic appreciation of tumour characteristics, and (5) a consensus opinion.

If the laryngeal tumour is early stage (T1a - T2a, with no involved neck nodes) then single modality treatment is required. If neck nodes are involved, or if the tumour is advanced (T2b – T4), multimodality treatment is required. Further consideration for multimodality treatment should be given to recurrent tumours or those with poor histologic features.

By thorough investigative work up, and tumour mapping by rigid endoscopy under general anaesthetic, the primary laryngeal tumour characteristics and sites of involvement are appreciated and directly affect staging and management. While glottic (vocal cord) sites are the commonest for laryngeal cancers, synchronous or metachronous second primaries are not uncommon, necessitating formal evaluation of other laryngeal sites (including the less obvious ventricles, anterior commissure and subglottis) and other mucosal sites in the upper aerodigestive tract. Main diagnostic methods include history, examination by flexible laryngoscopy or indirect laryngoscopy with neck palpation (including assessment of laryngeal crepitus) and cross-sectional imaging (CT skull base to mediastinum +/- chest, though MRI has been proven to be superior in staging laryngeal cancer), followed by rigid telescope endoscopy (under GA with 0, 30 and/or 70 degree scopes) and histological assessment of biopsies. Adjuncts in diagnosis include videostroboscopy, narrow band imaging and swallow assessments. These may provide information on depth of invasion, nerve involvement, field change, synchronous dysplasia or tumours, and effects of the tumour on function.

Important consideration should be given to altering treatment according to which laryngeal region is primarily involved. Glottic cancers have less lymphatic drainage and therefore better outcomes, whereas supraglottic cancers require consideration of locoregional (neck nodal) management, either in the form of bilateral selective neck dissections, or radiotherapy to the lymphatic regions of the neck. Subglottic cancers fare poorly overall, though often represent advanced spread of glottis cancers.

Treatment options for primary site

Single modality treatments for early laryngeal cancer include either surgery (endoscopic or open) or radiotherapy.

Endoscopic surgery typically refers to transoral laser surgery using the microscope. Treatment consists of one definitive laser procedure, followed variably by a re-look between 3-8 weeks later. The re-look may clear residual tumour rests, evaluate the healing and remove scar tissue. Other non-laser endoscopic options exist but are not standardized, particularly in early laryngeal cancers. Open surgery for early tumours refers to open partial laryngeal surgery, of which different types exist for specific tumours. Radiotherapy is the alternative to surgery, and conventionally consists of 6 - 7 weeks of irradiation, but short fractionation dose regimens have also been used.

The choice of treatment option depends upon tumour, patient and local clinician skillset variables. Patients should be offered an option of treatment based on these factors.

Consensus among tumour boards and current literature favour transoral laser resection for early laryngeal cancers (particularly glottic). This is in terms of voice outcomes, cost and treatment intensity benefits, prevention of a dry throat, and to hold radiotherapy in reserve. Open partial surgery remains an option but has largely been superceded by endoscopic approaches. This is dependent on institutional skills and patient selection. Radiotherapy remains an option for first line treatment in early laryngeal
cancers, where patients are unsuitable to have a laser procedure (either from comorbidities contraindicating a general anaesthetic, or tumour characteristics not favouring laser resection in that institution), or if the patient particularly chooses radiotherapy. For recurrences, see ‘Salvage’ below.

For advanced laryngeal cancers (either ≥ T2b primary tumour, unfavourable histologic characteristics such as perineural invasion, or nodal disease), multimodality treatment is required, with the exception of smaller T2b - T3 tumours, which may be considered for either surgery alone (total laryngectomy or in select cases and depending on expertise, partial laryngeal surgery by laser or open approach) or radiotherapy alone. Otherwise, treatment protocols differ between two options: surgery with postoperative radiotherapy (+- chemotherapy in more advanced cases); and concurrent chemoradiotherapy. Concurrent chemoradiotherapy should not be offered in T4 tumours that invade the thyroid cartilage. Two published facts make this treatment regimen as challenging as the stigma of a permanent stoma from laryngectomy: firstly CRT was labeled ‘organ preserving’, but evidence exists of severe toxic side effects (43% patients had late severe toxic effects; 11% dependent on tracheostomies and 19% on gastrostomies); secondly, no benefit in overall survival has been seen (but improved locoregional control and diminished distant metastases).

The former option of primary surgery followed by adjuvant treatment typically involves total laryngectomy with or without neck dissections, with adjuvant postoperative radiotherapy. An unequivocal advantage of primary surgery is precise histologic mapping of tumour and locoregional disease. Swallow and speech can be attained with both approaches described. While the stigma of a permanent stoma was the main drive for the ‘organ preservation’ concept, increasingly emphasis is placed on ‘functional preservation’.

Certain laryngeal tumours are unsuitable for concurrent chemoradiotherapy as primary treatment; large volume T4 tumours (thyroid cartilage invasion or >1cm tongue base involvement), pre-existing tracheostomy depicting organ failure (airway obstruction) or laryngeal destruction by tumour.

Neck treatment

In early stage glottic cancers (T1a – T2a N0) no treatment of the neck is required. This differs from early stage supraglottic cancers, where selective neck dissection or irradiation is required (levels II, III bilaterally).

In moderately advanced glottic and supraglottic cancers (T2b - T3 N0) selective neck dissection or irradiation is required to levels II, III, IV bilaterally.

The recommendation for advanced T4N0 glottic and supraglottic laryngeal cancers is neck dissection or irradiation bilaterally to levels II, III, IV, V and VI.

For positive nodal disease, treatment should be given to levels II, III, IV, V and VI on that side. If the opposite side has no nodal disease, the above principles apply. The choice of treatment can be neck dissection (with possible postoperative radiotherapy +- chemotherapy) or radiotherapy, depending on factors of nodal volume, degree of necrosis and prognostic information requirements.

Detecting recurrence

A big clinical challenge is accurately detecting laryngeal cancer recurrence, especially after chemoradiotherapy. Inflammatory oedema, fibrosis and even cartilage necrosis may affect biopsy sampling and interpreting, as well as misleading imaging. Deep or repeated biopsies may worsen infection, necrosis and symptoms. Both diffusion-weighted MRI and PET-CT are helpful and may guide the timing and site of biopsies.
**Salvage treatment**

Salvage treatment is offered for either recurrent or persistent disease. Persistent disease after radiotherapy is defined as radiologic or clinical (endoscopic) persistent tumour, and after chemotherapy is defined as less than a 50% response to chemotherapy at 12 week PET-CT scan.

If early laryngeal tumours recur after laser resection, then radiotherapy or open surgery are considered, with or without adjuvant treatment. Caution and vigilant monthly follow up should be practiced if laser is reconsidered in this setting. If early laryngeal tumours recur after radiotherapy, then a lower threshold for open surgery, either partial or total laryngectomy, is considered. Where features after surgery are unfavourable, consideration is given to re-irradiation (ideally by IMRT) or to chemotherapy.

If tumours that were an advanced stage recur, or if recurrences of early tumours are advanced, then salvage treatment options must be weighed up against palliation. If previously irradiated or only partial surgery was undertaken, then a total laryngectomy, bilateral neck dissection and low threshold for flap reconstruction should be considered. Increasingly local pedicled flaps (e.g. pectoralis major) are being routinely recommended in this scenario. Re-irradiation to new tissue can be considered. If previously primary complete surgery with no adjuvant therapy was performed, then radiotherapy +/- concurrent chemotherapy should be given. However, palliation needs to be considered if recurrence occurs after total laryngectomy +/- neck dissections and postoperative radiotherapy +/- chemotherapy.

**Inoperable laryngeal cancer**

Certain situations make a case inoperable: large volume T4 tumours where the patient is unfit for surgery, or a T4b tumour.

Options include best supportive care only, tracheostomy placement and palliation, debulking of tumour +/- tracheostomy and palliation, or radiotherapy with or without chemotherapy (even considering induction chemotherapy before concurrent chemoradiotherapy). Consideration should be given to the patient’s wishes, and airway, communication and nutrition, particularly if an endeavour is still radical.

**UNKNOWN PRIMARY SQUAMOUS CELL CARCINOMA**

**Definition**

An “unknown primary” refers to a neck nodal (lymphatic) metastasis of squamous cell carcinoma, without a known primary site.

**Decision Making**

Typically this presents as a mass in the neck, with few or no symptoms of significance in the upper aerodigestive tract. The patient may already have had investigation and treatment for the differential diagnoses of a neck lump (see below) with no resolution. The next steps are for fine needle aspiration for cytology (FNA) and referral to the head and neck clinic for work up. Most frequently, the primary site will be found in the head and neck region by thorough examination. This includes inspection and palpation of the oral cavity, oropharynx, thyroid, salivary glands, skin of the face, scalp and neck, and flexible rhinopharyngolaryngoscopy of the nasal cavity, nasopharynx, oropharynx, hypopharynx and larynx.

This specifically applies to squamous cell carcinoma yield on FNA. A question of lymphoma requires a lymph node biopsy. If equivocal FNA, then this is repeated with Immunohistochemistry.

The specific location of the neck mass correlates with well described lymphatic pathways in the head and neck. So, oral cavity lesions metastasize typically to level 1,2 and 3; oro- and hypopharyngeal and laryngeal lesions metastasize typically to levels 2, 3 and 4, and nasopharyngeal lesions typically to level
5. If the mass is supraclavicular, oesophageal, stomach, breast and pulmonary lesions should be considered, in addition to other distant sites.

In order to gain accurate diagnosis of the neck mass, FNA may be achieved with or without ultrasound guidance. While cross-sectional imaging by CT and MRI may be helpful as primary imaging together with CXR, the unknown primary is best investigated by a PET scan (ideally fused PET-CT).

The next step is a panendoscopy (rigid endoscopy under GA) with close attention to the nasopharynx, ipsilateral tonsil, tongue base, larynx and hypopharynx, and including also bronchoscopy and upper oesophagoscope. With previous PET imaging, a guided biopsy of the suspected primary site is now usually possible. Otherwise the traditional approach of an ipsilateral tonsillectomy and blind biopsies of several of the panendoscopy sites is utilized. Under GA, re-assessment of the neck mass ± further biopsy is possible. This can be by FNA, TruCut, core needle or open incisional or even excisional biopsy as required.

Open biopsy of neck masses, unless thought likely to represent lymphoma, is best avoided, due to possible spillage of cancer cells into the deep soft tissue and skin. If a multi-disciplinary team feels this is necessary, the best approach then is using an incision that can be re-used as part of an extended neck dissection subsequently. Frozen section use is rarely required. It is currently more acceptable to get a formal histological diagnosis and present the case for discussion. P16 status of the cytology or biopsy, indicating HPV aetiology, is important to request.

Management

Most unknown primaries arise from the oropharynx (tonsil or tongue base), or other sites within the head and neck. Rarely unknown primaries arise outside the head and neck. Cutaneous primaries, given the prevalence of skin cancer in South Australia, should be excluded.

Management decisions are based upon: (1) where is the primary site, (2) how advanced is the neck mass, (3) are distant primaries and distant metastases excluded, (4) what is the staging of the cancer, and (5) which modality is best to treat the squamous cell carcinoma.

An established fact is that the patient presents with a neck mass (meaning at least a stage III disease), so any neck dissection if used, needs to be either a modified radical or radical neck dissection. After any surgery, the case is then discussed again.

If the primary site is an accessible tumour, then surgery to primary site with a neck dissection is reasonable. Depending on the primary site, consideration must be given to a selective or more advanced neck dissection contralaterally too.

If the primary site is not accessible, and the neck mass is large or near the brachial plexus, then a neck dissection followed by adjuvant concurrent chemoradiotherapy is recommended.

The most contemporary decision-making debates relate to P16 (HPV) positive neck nodes. One typical regimen follows: If, after neck dissection, one node is positive for P16 without ECS, ipsilateral neck irradiation to the neck and oropharynx is offered. If the node is P16 negative, then irradiation from nasopharynx to cricoid is offered. If the neck shows ECS or N2B+ staging, radiotherapy with concurrent chemotherapy or Cetuximab is offered.

Patient and treatment factors may affect management options. However a standard workup, discussion and multi-disciplinary approach including dental, dietetic, speech and social work input is required. Importantly, in the event the primary site was never found (as still may occur but less frequently with the advent of PET scanning), the patient should adhere to close follow up regimens with a low threshold to re-investigate as clinically indicated.
REFERENCES

1 The South Australian Department of Health and The South Australian Cancer Network 2010, *Performance Indicator Framework for South Australian Cancer Services Version 1.0*, September 2010


10 Aboriginal and Torres Strait Islander Health Survey 2004-2005 National Health Survey and ABS 2004-2005.

11 Chong A Roder D 2008 Exploring

12 Aboriginal and Torres Strait Islander Health Survey (2004-2005), 2005, National Health Survey and ABS 2004-05.


25 Gessler S et al. Screening for distress in cancer patients; is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. Psycho- oncology 2007; 17:538-547.


29 ibid


33 The cancer council SA. Sexuality for women with cancer. A guide for women, their families and friends.


45 CALD steering committee for the Central Northern Adelaide Health Service. Cultural and linguistic diversity, a resource for health staff.


53 ibid

54 Australian Bureau of Statistics; Census 2011

55 CALD Steering committee for the Central Northern Adelaide Health Service. Cultural and linguistic diversity, a resource for health staff

56 ibid


127 Carr, Mm et al, 2000, Correlation of findings on direct laryngoscopy with presence of extraoesophageal reflux disease, Laryngoscope 110:1560-1562

128 Jacobi I et al 2010 Voice and Speech outcomes of chemoradiation for advanced head and neck cancers a systematic review. EAORL.2010;267:1495-1505


89 ibid


64 Royal Australasian College of General Practitioners. Putting prevention into practice (the Green Book) 2nded RACGP Melbourne 2006


138 Gillison ML, 2007 Current topics in the epidemiology of oral cavity and oropharyngeal cancers ,Head and Neck29:779-992


68 Cottrell J et al 2007, Comparing cancer profiles and survival of aboriginal and non-aboriginal patients in South Australia; where are the opportunities for improving Aboriginal health? Asian 8:495-501

69 Cottrell J et al 2007, Comparing cancer profiles and survival of aboriginal and non-aboriginal patients in South Australia; where are the opportunities for improving Aboriginal health? Asian 8:495-501


71 ibid


75 Oncoline clinical practice Guidelines; Head and Neck, Diagnosis 2007, www.oncoline.nl


79 ibid

80 ibid

91 Mahon SM, Cella DF, Donovan MI. Psychosocial adjustment to recurrent cancer. Oncology Nurses Forum 1990; 17:47-52
94 Sciubba JJ, End of life considerations in the head and neck cancer patient, Oral oncology, 2009;45(4-5):431-4
99 Cancer Follow-up; Towards A Personalised Approach to Aftercare Services. Review Of Current Practice and Selected Initiatives; Macmillan Cancer Support Nov 2009; NHS UK
103 Fitch, M 2000,Supportive care for cancer patients;. Hospital Quarterly, Volume 3, no 4, pp 39-46


