Head and neck cancer case based learning resource Overview of the head and neck cancer case study: Mrs. Li's story

This case study recounts the experience of Mrs. Li, a 55-year-old female diagnosed with head and neck cancer.

The case study contains five sections:

- 1. Reduce risk.
- 2. Find the condition early.
- 3. Have the best treatment and support during active treatment.
- 4. Have the best treatment and support between and after active treatment.
- Have the best care at the end of life.

It is recommended that you complete the sections and their related activities in order. This is because each section and each activity includes information that will help you complete the sections and activities that follow.

Learning activities

At times, you will have learning activities to complete. Click on the learning activities button and a list of questions will pop up. The questions will relate to the content you've just read or the video you've just watched.

Videos

There is a video component to this case study that is presented in nine parts. You can watch the video clips when prompted throughout this case study, or at any time by clicking on the video icon in the right-side menu. Learning activities throughout the case study will discuss the video and ask questions about it.

Your notebook

Use your notebook at the top of the screen to record your thoughts and answer learning activity questions. You can print your notes by clicking the print icon within the notebook.

Resource links

Resource links are included throughout the case study. These links lead to interesting articles or websites, and are designed to encourage you to explore other available resources.

PDF of head and neck cancer module

You can download a PDF version of the head and neck module.

Suggested citation:

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Aim of the head and neck cancer case study

This case study aims aim to facilitate the development of competencies that reflect the role of the Specialist Cancer Nurse (SCN) in ensuring a coordinated approach to care planning, implementation and evaluation across the cancer journey for people affected by head and neck cancer.

Rationale

The incidence of head and neck cancers is relatively low. However, people affected by these cancers often receive intense medical, nursing and allied health support during their cancer journey due to the complexity of the disease, multimodal treatments, and disruptive side effects and symptoms.³

This complexity requires that the person's care be well coordinated.

There are many points along the cancer journey when the SCN can improve outcomes for people at risk of or affected by this disease. These include:

Section 1: Reduce risk

Factors identified as increasing risks for the development of head and neck cancer include:3-5

- heavy alcohol and/or tobacco use
- a poor or imbalanced diet
- exposure to carcinogens and co-carcinogens
- possible vulnerabilities caused by genetic factors or the human papilloma virus.

The SCN can play an important role in public health efforts that promote understanding of these risks.

Section 2: Find the condition early

There are no definitive screening processes that can detect head and neck cancers early.⁶

People who present early with few symptoms and localised disease are likely to require less invasive treatment and thus achieve better outcomes, including cosmetic results.^{3, 6} Symptoms may include:⁶

- localised pain
- hoarse voice
- difficulty swallowing
- swelling
- mouth ulcers
- leukoplakia of oral mucosa
- bad breath.

Targeted public health initiatives to raise awareness of the importance of these symptoms within high risk groups may improve rates of early detection.

Section 3: Have the best treatment and support during active treatment

Treatment for head and neck cancers may include a combination of surgery, antineoplastic agents, radiotherapy and biotherapies. A coordinated approach to care planning, delivery and follow up is required to ensure continuity of care.

Treatment effects and symptoms have the potential to significantly impact many areas of a person's life, such as:^{3, 7, 8}

- body image
- nutrition and hydration
- communication
- mobility
- capacity to work and socialise.

SCNs, in collaboration with members of the multidisciplinary (MDT) team, have a major role in minimising the impact of these treatments and coordinating the range of services and care providers involved in the person's treatment program.

Section 4: Have the best treatment and support between and after active treatment

The physical, psychological, practical and informational needs related to head and neck cancer require intervention from the MDT.³

A range of supportive care needs may be experienced by people affected by head and neck cancer including:³

- altered communication
- altered nutrition and swallowing
- oral and respiratory effects and symptoms
- pain and other discomforts
- anxiety
- psychological distress related to body image
- depression
- altered social relationships.

The SCN is well placed to play a key role in coordinating multiple health services in response to the needs of people who have received treatment for head and neck cancer, assisting them to resume activities of daily living, occupation, and social interaction.⁹

Section 5: Have the best care at the end of life

Advanced cancer impacts on the quality of life of the individual and their family or caregivers in many ways, as it can be associated with:¹⁰

- distressing physical symptoms
- deterioration of physical functioning
- increasing psychological distress
- increasing disruption to social activities
- challenges to existential and spiritual wellbeing.

The SCN, as part of the MDT, provides individualised, evidence-based supportive care to respond to these needs.

Section 1: Reduce risk

Objectives

On completion of this section, you should be able to:

- 1. Interpret key epidemiological trends in age specific incidence, mortality and survival from head and neck cancer.
- 2. Explain current evidence regarding risk factors associated with the development of head and neck cancers.
- 3. Promote access to information, resources and health services, appropriate to individuals' circumstances, to reduce the risk of head and neck cancer.

Head and neck cancer in Australia

In 2013, 4409 new cases of head and neck cancer were diagnosed in Australia, accounting for 3.4% of all cancers diagnosed. ⁵⁰ The incidence is highest in men, with 3174 of the new cases in men and 1234 in women. ² The most common forms of head and neck cancers in 2013 were: ⁴⁸

- lip (1047 cases)
- tongue (820 cases).

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In 2013, the risk of developing lip and tongue cancer before the age of 85 was 1 in 199 and 1 in 263 respectively. 48

In 2013, the mean age at diagnosis with tongue cancer was 62.8 years and with lip cancer it was 63.7 years. ⁴⁹ The risk of being diagnosed with head and neck cancer increases with age. Whilst the number of head and neck cancers is expected to continue rising for both males and females due to the ageing of the Australian population, of the more common forms of head and neck cancer (lip, tongue and larynx), incidence and mortality rates have decreased or remained fairly stable. ^{1, 11, 12}

In 2014, head and neck cancer was the 15th leading cause of cancer death in Australia. In 2014, there were 1,040 deaths from head and neck cancer in Australia (766 males and 274 females). The number of deaths from head and neck cancer increased from 517 (374 males and 143 females) in 1968 to 1,040 in 2014. ⁵⁰

In 2009–2013, individuals diagnosed with head and neck cancer had a 69% chance (68% for males and 72% for females) of surviving for 5 years compared to their counterparts in the general Australian population. ⁵⁰

Between 1984–1988 and 2009–2013, 5-year relative survival from head and neck cancer improved from 61% to 69%. 50

Learning activity	
Completed	 Access the document Head and neck cancers in Australia (2014)² and, for one type of head and neck cancer, compile information on the following: Incidence, mortality and survival trends. Relative five and ten year survival rates. Factors associated with survival. Prevalence.

Risk factors

Smokers, heavy alcohol users, and betel nut/tobacco chewers have a higher risk of developing head and neck cancer.³

In the UK, the proportion of cancers linked to tobacco use include:5

- 70% of mouth and pharynx cancers in men
- 55% of mouth and pharynx cancers in women
- 79% of larynx cancers in men and women.

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Convincing evidence has linked the diagnosis of cancer to alcohol use. The attributable fraction has been estimated at:¹³

- 16.9 41% of mouth and pharynx cancers
- 27.3 44% of laryngeal cancers in men
- 12.2 41% of laryngeal cancers in women
- 25.3 51% of oesophageal cancers in men
- 11.3 51% of oesophageal cancers in women.

The combined effect of drinking alcohol and smoking tobacco greatly increases the relative risk of developing mouth and throat cancers by more than 35 times.¹³

An imbalanced diet is often associated with smoking and heavy alcohol use, which exacerbates the risk of head and neck cancer. Consumption of salted meat and fish such as those included in an Asian style diet have also been implicated. Consumption of non-starchy vegetables and fruit is associated with a protective effect against cancers of the digestive tract including cancers of the mouth, larynx, pharynx, oesophagus and stomach.

Occupational exposure to the following known carcinogens and co-carcinogens have also been linked with development of head and neck cancers:⁴

- asbestos
- fuel fumes
- formaldehyde
- hydrocarbons
- dust particles from various sources.

Studies have demonstrated possible genetic vulnerabilities for developing primary or secondary head and neck cancer. 16

The human papilloma virus has been recognised as a risk factor for a discrete set of head and neck cancers (oral cavity and oropharyngeal squamous cell cancers), and its recognition has significant preventive and therapeutic implications. ^{6, 14, 17}

Many of these risk factors are more prevalent in socially disadvantaged groups, with the risk of developing head and neck cancer often higher among these groups. Tailored interventions are required to promote awareness among these populations about reducing their risk or identifying cancers early.³

Resource links

<u>Head and neck cancer in Australia between 1982 and 2005 show increasing incidence of potentially HPV-associated oropharyngeal cancers.</u> 2011. British Journal of Cancer¹⁸

A study of head and neck cancer treatment and survival among indigenous and non-indigenous people in Queensland, Australia, 1998 to 2004. 2011. BMC Cancer¹⁹

Learning activities			
Completed			
	In your practice setting, outline how you would refer an individual to services and resources aimed at facilitating smoking cessation.		
	You are asked to explain to nursing students what evidence exists about the risks of alcohol and the development of cancers. Describe how you would summarise and explain current evidence.		

Section 2: Find the condition early

Objectives

On completion of this section, you should be able to:

- 1. Identify the early signs that may indicate a diagnosis of head and neck cancer.
- 3. Identify factors which may act as enablers and barriers to early detection of head and neck cancer
- 4. Describe common concerns and reactions of people with symptoms which may be associated with head and neck cancer.
- 5. Implement strategies to provide information, education and support to improve early detection of cancer in people from culturally and linguistically diverse (CALD) groups.

Early detection

Stage at diagnosis is the most predictive factor for survival from head and neck cancer and of cosmetic outcomes.¹⁷

Earlier detection and treatment is linked with improved prognosis. There is, approximately, a 50% survival advantage in people with early stage disease compared with locally advanced (Stage 3 or 4) disease.⁷

Around 60% of people with head and neck cancer present with advanced disease. Locally advanced disease and the extent of regional lymph node involvement are predictors of poor outcomes for this population.²⁰

Australian guidelines recommend review of the following potential symptoms of head and neck cancer by the general practitioner (GP) if they persist for more than three weeks (especially if there is more than one symptom):^{3, 21}

- hoarse voice
- difficulty swallowing
- persistent sore throat (particularly together with earache)
- neck or parotid lump
- mouth ulcer or mass
- leukoplakia of oral mucosa
- non-dental mouth or jaw pain (especially with difficulty opening the mouth)
- altered speech
- spitting up blood.

Prompt referral from the GP to a specialist surgeon is recommended if symptoms are present.³

Diagnosis of a head and neck cancer is confirmed via a biopsy of the primary tumour or fine needle aspiration of a neck lump and CT scan with contrast.^{3, 21}

Learning ac	Learning activities			
Completed				
		Outline the signs and symptoms of early and advanced head and neck cancer.		
		Access the Cancer Council Wiki <u>Clinical practice guidelines for the diagnosis and management of Barrett's Oesophagus and Early Oesophageal Adenocarcinoma</u> to learn about the role of Barrett's Oesophagus in the development of oesophageal cancer.		
		Access the resource Neck lumps: a diagnostic guide for general practitioners. Identify signs and symptoms of two types of head and neck cancer.		

Strategies to support early detection in culturally and linguistically diverse (CALD) groups

Access to health services by CALD communities may be impeded by their lack of familiarity with the complex Australian health system, and lack of consideration of the health and spiritual beliefs of different cultures.²²

Some factors identified as influences on participation of CALD background communities in health promoting activities are: 22

- English language proficiency
- insensitivity to the needs of CALD background communities
- family responsibilities
- social isolation
- access to transport
- cost.

There may also be further cultural restrictions and imperatives specifically affecting women and their ability to access health care.

Factors which have been identified that may improve uptake of health related activities include:²²

- appropriate publicity of activities
- use of peer educators, role models and champions to engage CALD background communities
- activities to raise awareness of and encourage access to the variety of culturally appropriate services available
- delivering health services in a consumer's preferred setting
- family involvement in decision making
- opportunities to increase confidence and general skills and to see practical benefits
- having a range of activities in one venue catering for different ages, genders and skill levels
- working in partnership with key CALD background communities to increase community capacity building and encourage participation in different activities.

Learning activities			
Completed			
	Access <u>Cultural competence in health: A guide for policy, partners and participation</u> . 2005. NHMRC ²²	ships	
	Discuss examples of how cultural meanings of cancer for people f different CALD backgrounds might impact on early detection initial		
	Describe tailored community interventions which may encourage presentation for people from CALD backgrounds.	early	

Case Study: Meet Mrs. Li

Case study: meet Mrs Li

Mrs Li is a 55-year-old female diagnosed with head and neck cancer. This case study follows Mrs Li from diagnosis to the end of her life.

After reading the health history and watching the video, work through the learning activities. Use your notebook at the top of the screen to answer the learning activity questions and record your thoughts.

Health history

Patients name: Li Xiang (non-smoker)

Sex: M□ F 🗹

Age: 55

Other Details: Marital status:

Married - husband, Li Chen (60), works in family business (restaurant), smoker

Children:

Son, Li Jin (38), married with children, works in family business, smoker

Daughter, Li Ying (Tamsin) (26), unmarried, living at home, working full-time, non-

smoker

Place of Birth:

Suzhou, Jiangsu Province, China. Moved to Australia 25 years ago

Main language spoken at home:

Cantonese

Previous employment: Silk/textile industry

Current address: Well-established Chinese-Australian community within a large

metropolitan city

Diet:

Traditional Chinese diet maintained

Case study: meet Mrs Li

In this video, Mrs. Li's daughter Tamsin describes the symptoms that prompted the family to seek further intervention.

Mrs Li's story 1: symptoms



Learning activities	;	
Completed		
	1	Identify risk factors Mrs Li has in relation to head and neck cancer.
	2	Explain strategies which could reduce the risk of head and neck cancer in the Li family.
	3	Outline how you would identify the implications of Mrs Li's cultural background in implementing risk reduction strategies.
	4	Identify services and strategies which could facilitate earlier presentation of symptoms for people, such as Mrs Li, who come from CALD backgrounds.
	5	Access Section six, step two of the <u>Initial diagnosis and referral within</u> the Patient Management Framework for head and neck tumour stream ³ and:
		 Discuss potential supportive care interventions which may assist the Li family through the diagnostic process.
		 Describe processes or practices that would facilitate coordination of Mrs Li's care at this stage in the cancer journey.

Section 3: Have the best treatment and support during active treatment

Objectives

On completion of this section, you should be able to:

- 1. Describe the pathophysiological features of the different types of head and neck cancer.
- 2. Discuss the implications of staging and histopathology of head and neck cancer for a person's cancer journey.
- 3. Discuss key supportive care needs of people diagnosed with and undergoing treatment for head and neck cancer.
- 4. Justify an MDT approach in coordinating care for people affected by head and neck cancer.
- 5. Discuss current treatment approaches for the management of different types and stages of head and neck cancer.
- 6. Analyse factors that might influence the treatment decisions of people with head and neck cancer.
- 7. Use evidence-based approaches to facilitate the ability of the person affected by head and neck cancer to participate in decisions about their treatment and care, according to their preferences.
- 8. Implement evidence-based interventions to respond to the supportive care needs of people affected by head and neck cancer.
- 9. Tailor supportive care interventions to an individual's personal and social circumstances.

Types and staging of head and neck cancers

Head and neck cancer describes a group of malignancies arising in the:¹⁷

- lip
- oral cavity
- pharynx
- larynx
- paranasal (ethmoid and maxillary) sinuses
- salivary glands.

Histologically, most head and neck cancers are squamous cell carcinomas (SCCs).¹⁷

It is recommended that adults with lateral neck lumps should be actively investigated to exclude malignancy. A biopsy of the primary tumour or fine needle aspiration of a neck lump should be obtained, and assessed by a pathologist experienced in head and neck cancer.⁸

Staging involves clinical and endoscopic examination and appropriate imaging. Synoptic reporting is encouraged with pathological staging following surgical resection.³

The tumour, node, metastasis (TNM) staging system is used for head and neck cancer with some variations in descriptors based on disease site. In general, stage I or II cancers are relatively small primary tumours with no nodal involvement. Stages III and IV cancers include large primary tumours which may invade underlying structures and/or spread to regional nodes.¹⁷

Learning ac	Learning activities			
Completed				
		1 Review the anatomy and physiology of the head and neck region to:		
		 Identify the sub-sites affected by cancers of the oral cavity, pharynx and larynx. 		
		Identify regional lymph node distribution.		
		2 Access the NCI Oropharyngeal Cancer Treatment (PDQ) General Information website ²³ and:		
		 Discuss why tumours at the base of the tongue are considered insidious and often present at an advanced stage. 		
		Outline the staging and classification of oropharyngeal cancer.		

MDT care for head and neck cancer

The management approach offered to the person affected by a head and neck cancer is complex and depends on factors such as site, extent and pathology of disease.

Although achieving cure or control of the cancer is the primary goal of treatment, preserving the function of the nearby nerves, organs, and tissues is also very important. Where possible, consideration is given to the effects of the treatment on a person's quality of life, such as how they may feel, look, breathe, eat, and speak.³

Physical needs commonly experienced by people affected by head and neck cancer include:³

- communication difficulties
- nutritional deficiency
- swallowing difficulties
- oral changes
- respiratory symptoms
- pain
- sexual dysfunction
- general debilitation.

In accordance with current best practice for management of head and neck cancer, people with a diagnosis should be referred to a specialist MDT for assessment, treatment planning and ongoing management of their disease, side effects and symptoms.^{3, 17}

The development of teams with sufficient caseload to build expertise and experience in the management of these cancers is encouraged.³ These teams require specialist nursing, allied health and psychological support services, as people diagnosed with head and neck cancer may have a range of information and support needs that require intervention, including:³ 17

- strategies to manage anxiety
- strategies to ensure adequate nutritional support
- support for body image issues
- treatment for depression
- assessment for laryngectomy aids
- assistance with smoking cessation or alcohol withdrawal.

Learning activities			
Completed			
		1	Discuss the requirements of a specialist treatment facility to manage the care of a person diagnosed with head and neck cancer.
		2	Identify and explain the role of various health professionals in the MDT that care for people affected by head and neck cancer.
		3	Describe the role of a head and neck cancer care coordinator.
		4	Discuss how a model of care such as early intervention clinics may be effective in the management of head and neck cancer.

Case study:

Mrs Li's story 2: multidisciplinary care



Learning activ	vities		
Completed			
I		5	Reflect on the family relationships and cultural background within the case study, and:
			Discuss how Mrs Li's care could be enhanced through knowledge of family values and health beliefs.
			 Explain how you would develop an understanding the implications of Mrs Li's beliefs, values and customs in planning her care.
I		6	Explain issues to be considered if Mrs Li's daughter is involved in interpreting the discussions with the health professionals for her mother.
1		7	If Mrs Li was admitted to your health facility, describe how you would ensure access to supportive care services to meet her needs related to her culture and communication.
		8	Explain strategies for improving the process of diagnosis and referral for Mrs Li and her family to ensure a coordinated care approach.

Treatment approaches for head and neck cancer

Head and neck cancer management is complex due to the multiple sites, stages and histologies. Management approaches are determined by individual and health professional preferences and clinical factors including tumour site, extent of disease, treatment morbidity, nutritional status and concomitant health problems. Single modality treatment with surgery or radiotherapy is generally recommended for early stage disease and combined modality approaches are delivered for locally or regionally advanced disease at diagnosis. As a diagnosis.

It is recommended that all individuals are evaluated by an head and neck surgical oncologist before treatment.¹⁷ Surgery is used as a single or combined treatment modality. The intent for surgery in stage I and II disease is curative.²⁴ In advanced stages, surgery reduces tumour size, improves quality of life and enables continuing therapy with adjuvant approaches.²⁴

Apart from many early SCCs of the mouth and oropharynx that can be cured by excision, radiation therapy is the usual preferred primary treatment for early tumours at other sites.³ Intensity-modulated radiotherapy (IMRT) is widely used in head and neck cancers.¹⁷

Gene therapy and immune system targeting are newer treatment modalities for head and neck cancer. Through a combination of viral and nonviral vectors, immune stimulation, and monoclonal antibodies, researchers are working to attack cancer at the cellular and molecular levels. Localisation of specific tumour antigens, such as the mutated p53 tumour suppressor gene product found in 80% of SCCs, is helping to guide some of these new therapies.²⁵

Learning activities	
Completed	
	Access these key head and neck cancer treatment guidelines before completing the following activities:
	 Patient Management Framework. Head and neck tumour stream: larynx, pharynx and oral cancer: a guide to consistent cancer care. 2006. Victorial Government Department of Human Services³
	 Head and Neck Cancers Version 1.2014. 2014. National Comprehensive Cancer Network¹⁷ (This is a free resource, but you must register and click 'Remember me' to bypass the login page in future)
	Describe the key tumour related factors which will be considered in planning head and neck cancer management.
	2 Explain the role of health related quality of life assessment in treatment planning for head and neck cancer.
	Refer to current guidelines and outline recommended treatment options for a person with Stage IV (T3N2) oropharyngeal cancer.

Supportive care needs following treatment

The physical and psychological impact of head and neck cancer and its treatment are significant. Due to the exposed position of the disease, scars, defects and disfigurement are noticeable. Vital organs for ingestion and breathing, as well as cranial nerves and vessels may be compromised by the disease and / or its treatment.²⁴

Common surgical complications in head and neck cancer include:24

- dysarthria
- dysphagia
- flap failure
- wound infection
- delayed wound healing
- wound dehiscence
- haemorrhage.

The extent of post-surgical swallowing difficulties varies depending on site and extent of resection and the need for reconstruction. Surgical interventions for oral cancers may cause odynophagia, reduced sensation, reduced ability to manipulate food and form a cohesive bolus, reduced anterior-posterior tongue movements to trigger the reflex, poor lip seal causing drooling and reduced or absent sense of taste and/or smell.

Surgical interventions for pharyngeal and laryngeal cancers may cause odynophagia, reduced sensation, increased risk of aspiration and post-surgical strictures. Permanent or temporary tracheostomy tubes also disrupt the swallowing process.²⁶

Pain, nausea, vomiting and fever are important symptoms to manage to promote effective wound healing.²⁴

Common acute reactions to radiotherapy include:²⁷

- oropharyngeal mucositis
- dysgeusia
- zerostomia
- fatigue.

Clinically the individual may experience dehydration and significant weight loss as a consequence. ²⁷ Concurrent radiotherapy and antineoplastic agents increase acute toxicity compared to radiation alone. ¹⁷

An individual's adjustment to the challenges of head and neck cancer and its treatment relies on:²⁸

- the degree of their disfigurement
- the emotional value they place on their altered appearance
- how comfortable they now feel in managing interactions with others
- the quality of the support they receive from family and friends.

Undertaking a thorough pretreatment assessment is essential, and providing individualised education about postoperative functionality may enhance a sense of control and reduce anxiety by allaying fears and expectations.¹⁷

Assessment of the types of support and coping skills individuals possess is crucial for effective supportive care. Family and friends may need to be coached on how to give positive and realistic reinforcement to encourage rehabilitation.

The SCN is well positioned to screen, undertake focused assessments and refer people affected by disfiguring surgery for specialised support services. Access to supports through the community is also required upon discharge.²⁸

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Postoperative complications in head and neck cancer. Clinical Journal of Oncology Nursing. 2012²⁴

Learning activities		
Completed		
	1	Describe what is involved in excision of the primary tumour at the base of tongue and ipsilateral comprehensive neck dissection, in terms of:
		potential complications
		 pre-operative and post-operative nursing care requirements.
	2	Outline the procedures used to assess an individual's swallow following treatment for head and neck cancer.
	3	Discuss the impact across all domains of health of altered swallow post head and neck cancer treatment.
	4	Discuss how the SCN can facilitate a coordinated approach for care following surgery for head and neck cancer.
	5.	Access the COSA Wiki Evidence-based practice guidelines for the nutritional management of adult patients with head and neck cancer and:
	•	Discuss how head and neck cancers can cause nutritional impairment
	•	Identify the issues to consider when providing nutritional support for patients undergoing chemotherapy or radiotherapy as part of their treatment for head and neck cancer.
	5	Access the article Chemotherapy and biological agents in the clinical management of head and neck squamous cell carcinoma ²⁹ , and:
		 Identify three antineoplastic agents used in the treatment of head and neck cancer and outline the rationale for their use with radiotherapy.
		 Describe the relevance of the timing and sequencing of antineoplastic agents and radiotherapy within a prescribed protocol for head and neck cancer.
	6	Access the article <u>Nutritional Support During Radiotherapy for Head and Neck Cancer: The role of prophylactic feeding tube placement</u> ²⁷ , and:

 Explain the pathophysiology of nutritional effects of head and neck cancer treatment.
 Summarise evidence based methods of nutrition related assessment of the person affected by head and neck cancer and its management.
Access the article <u>Putting evidence into practice: evidence-based</u> <u>interventions for the management of oral mucositis</u> ³⁰ , and summarise key recommendations for nursing management of oral mucositis.
Outline current prevention and management strategies for head and neck radiation skin reactions in your care facility. Discuss current evidence to support the use of these strategies.

Case study

Mrs Li's story 3: concurrent chemoradiation



Learning activity		
Completed	Discuss disease, treatment and individual person related factors that influence the obtaining of Mrs Li's informed consent prior to treatment of head and neck cancer.	

Health history	
Patients name: Sex:	Li Xiang M □ F ☑
Age:	55
Following diagnosis:	-Surgical excision of primary tumour and ipsilateral comprehensive neck dissectionStaging indicates T3N2M0Confirmed diagnosis of Stage IV head and neck cancer at the base of tonguePost-operative chemoradiation is indicated due to the finding of extra-capsular nodal spread. It is recommended chemoradiation is started six weeks post resectionRadiation therapy will be daily for six weeks. Proposed therapy involves single agent cisplatin at 100mg/m2 every three weeks for three doses.

Learning activities		
Completed		
	Discuss the likely prognosis for provided.	Mrs Li in light of the information
	Outline the intent of Mrs Li's tr	eatment plan.
	Explain the rationale for the re combined modality treatment.	commendation that Mrs Li receives
	· · · · · · · · · · · · · · · · · · ·	ns associated with the combined r Mrs Li, and the associated nursing
		port required by Mrs Li and her family to treatment and management of
	Outline the potential role of pr care of Mrs Li.	ophylactic feeding tube placement in the

Complementary and alternative therapies

Complementary and alternative therapies are a group of diverse medical and healthcare practices, products and systems not currently considered part of conventional medicine.³¹

Studies have reported 17 to 87% of people receiving conventional cancer treatment use of at least one form of complementary therapy.³¹ Furthermore, it is believed that significant numbers do not disclose their alternative therapy use to health professionals.³² It is recommended that health professionals become more diligent in assessing the use of complementary and alternative therapies by people affected by cancer.

Some therapies have effects as powerful as traditional medical treatments, which may impede, alter or enhance the treatment prescribed by western medical practitioners. This may lead to potentially negative treatment results.³³

Traditional Chinese medicine dates back to 1500 BC and takes various forms, some of which are considered alternative therapy by western cultures. These include:³²

- acupuncture
- dietary therapy
- meditation and the mind-body therapies (such as Qigong and Tai Chi)
- herbal medicine.

Resource link

Position Statement. Complementary and alternative therapies. Cancer Council Australia. 2013³¹

Learning act	ivities		
Completed			
		1	Define the following terms:
		•	Complementary therapies.
		•	Alternative therapies.
		•	Conventional therapies.
		•	Integrative medicine.
		2	Identify the various sources of information available for the public in relation use of complementary and alternative therapies in cancer, and the strengths and limitation of these sources.
		3	Outline reasons that a person with cancer may choose to use complementary and alternative therapies.
		4	Discuss resources and approaches to facilitate assessment and open communication about the use of complementary and alternative therapies by people affected by cancer.

	5 Explain the role that complementary and alternative therapy practitioners may have in an MDT.
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Case study

SCN and the use of CAMs

Mrs Li's story 4: alternative

medicines



Learning activities			
Completed			
		6	Discuss how you would respond to Mrs Li's use of traditional Chinese medicines, providing evidence based rationales for your response.
		7	Describe how you would assess the benefits and risks associated with the CAMs Mrs Li may be using.
		8	Describe how you would facilitate communication between Mrs Li and her family and health professionals about her use of CAMs.

Section 4: Have the best treatment and support between and after active treatment

Objectives

On completion of this section, you should be able to:

- 1. Explain the short and longer term supportive care needs of people following completion of primary treatment for head and neck cancer.
- 2. Implement evidence based clinical and supportive care nursing interventions for the person following completion of primary treatment for head and neck cancer.
- 3. Collaborate with other care providers to ensure a coordinated, planned approach to meeting supportive care needs for the person following primary treatment for head and neck cancer.
- 4. Promote access to information and resources for the person affected by head and neck cancer to enable continuity of their care.

Following treatment

An individual's quality of life post treatment for head and neck cancer are impacted by their resultant physical, cognitive, emotional and social function.²⁴ The complexity of treatment approaches within the vicinity of essential anatomical structures of the head and neck frequently leads to persistent chronic effects, affecting: ^{17, 34}

- swallowing
- voice
- taste
- airway control
- nutrition
- mouth (xerostomia dry mouth)
- bones (osteoradionecrosis)
- psychiatric functioning
- hearing.

Measurable sensorineural hearing loss following radiation and chemotherapy, such as cisplatin, has been reported in people treated for nasopharyngeal cancer. Risk factors for developing hearing loss were identified as older age (older than 50) and pre-treatment hearing deficit.³⁴

An essential component of head and neck cancer management is ongoing monitoring of the status of the disease, management of these effects, and rehabilitation after initial treatment. Clinical examination is the recommended approach for monitoring of the status of disease, rather than intensive investigations.

Thyroid stimulating hormone (TSH) should be monitored regularly in individuals who have received neck irradiation. Approximately 20-25% of individuals have increased levels and they are at risk of hypothyroidism. Speech, hearing and swallowing evaluation and rehabilitation and dental evaluation should be undertaken as indicated in individual circumstances. Cosmetic appearance, swallowing, speech, chewing, nutritional status and psychosocial functioning are all monitored as part of the rehabilitation process.

The rehabilitation team might consist of the following health professionals, who all contribute to the individual's quality of life:^{3, 7, 24}

- nurses
- speech pathologists
- social workers
- physiotherapists
- prosthodontists
- occupational therapists
- dieticians
- psychologists
- doctors.

Care coordination is essential to ensure that the needs of the person affected by head and neck cancer are met by the right health professional, at the right time, in the right sequence. Excessive follow up by multiple specialists can be prevented by the development of a clear follow up plan. The plan will vary depending on the treatment intent and individual responses to disease management.³

The individual's family/carer needs to be involved in discharge planning. Reinforcement of information and education through skills training, written plans and telephone follow-up are recommended. A

multidisciplinary approach to education is required. The amount of information can be overwhelming, so health professionals should reinforce teaching whenever possible.²⁴

Learning activities	;	
Completed		
	1	Outline factors which influence the recommended follow-up regimen for a person following primary treatment for head and neck cancer.
	2	Describe interventions which may facilitate continuity of care for a person following primary treatment for head and neck cancer.
	3	Outline the role of the General Practitioner in coordination of follow up care for people with head and neck cancer.
	4	Discuss your actions if a person doesn't have a nominated General Practitioner for follow up care.
	5	Discuss the evidence-based management strategies of the following chronic conditions following treatment for head and neck cancer:
		impaired swallowing
		• xerostoma
		taste alteration.

Case study

Mrs Li's emergency admission.

Mrs Li's story 5: following treatment



Learning activities		
Completed		
		Describe potential physical, psychological and social challenges for Mrs Li and her family after discharge from active treatment.
		7 Discuss how such an emergency could be avoided in future.
		8 Discuss strategies and processes to ensure coordinated care is maintained for Mrs Li's emergent admissions.

Head and neck cancer recurrence

As many head and neck cancers are detected at a later stage, recurrence of the disease can occur in many cases. Treatment of a head and neck cancer recurrence will depend on the individual's performance status and wishes, location and extent of the recurrence, and on previous management.

Treatment may include surgery (salvage surgery or could be extensive for local recurrence), radiotherapy (local recurrence), and/or drug therapy (in association with radiotherapy or for palliation of symptoms).^{3, 17} If treatment is feasible at this time, the treatment goal is cure. Recurrent disease which is not amenable to approaches with curative intent necessitates palliative management approaches used for metastatic disease.¹⁷

Learning activity		
Completed	Discuss possible psychological and spiritual needs of a person diagnosed with recurrence of head and neck cancer.	

Section 5: Have the best care at the end of life

Objectives

On completion of this section, you should be able to:

- 1. Analyse the SCN's role in facilitating the transition to palliative care for people affected by head and neck cancer.
- 2. Examine the cultural, spiritual and supportive care needs for people affected by head and neck cancer at the end of life.
- 3. Facilitate the implementation of a plan that incorporates all health and support services required to provide end of life care to people affected by head and neck cancer.

Treatment approaches during the palliative phase

Participation in clinical trials may be recommended for individuals with advanced head and neck cancer. For example, interstitial photodynamic therapy (PDT) has been trialed in a phase 1-2 study as salvage treatment for recurrent head and neck cancer. PDT is a site specific tumour treatment involving the administration of a photosensitiser followed by focal activation in the presence of oxygen using light of a wavelength matched to an absorption peak of the photosensitiser. It can be applied safely to previously irradiated tissues. It is suggested that it may become a useful therapeutic option for advanced head and neck cancer. 35, 36

Palliative treatment approaches can include radiotherapy to areas of symptomatic disease, analgesics and investigational agents.³⁷

It is recommended that palliative treatment approaches are dictated by the person's performance status and their preferences. For individuals with poor performance status, the best supportive care may be offered. Ensuring appropriate types and levels of health care is provided to people at the end of life is critical to ensuring optimal outcomes.

Learning activity		
Completed	Discuss principles for facilitating informed consent for treatment and supportive care interventions for the person with advanced head and neck cancer.	

Assessment during the palliative phase

Comprehensive assessment of a person's health problems and needs is an important component of all care at the end of life. It ensures that health professionals can tailor interventions to suit individual needs and preferences and, importantly, it ensures that reversible causes of problems can be addressed.

A person's quality of life can improve with appropriate interventions and/or treatments of reversible symptoms.

The following factors will influence the nature of treatment options in each individual case:³⁸

- awareness of the prognosis
- knowing the natural history of the person's life-limiting illness
- knowing where and how they perceive themselves on the course of their illness.

Cultural background, spiritual beliefs and social circumstances can also influence needs and services required.

Learning activities		
Completed		
	1	Outline the key components of a comprehensive assessment for the person with head and neck cancer at end of life.
	2	Explain how assessment of functional status and phase of illness can guide nursing intervention.
	3	Distinguish between the palliative interventions provided by various members of the MDT for a person with advanced head and neck cancer.
	4	Identify factors which determine the need for referral to palliative care.
	5	Outline the referral process to the palliative care service in your health care facility.

Culture and end of life care

Cultural safety in end of life care requires both an understanding of and a respect for cultural difference, to enable change in clinical practice to reflect this understanding. Some beliefs and practices of Chinese Australians in relation to death and dying include:⁴

- being more conservative in their views about autonomous decision-making and truthful or open communication
- having tendencies to strict hierarchy and family solidarity which includes the notion of filial piety
- being more submissive and taking a collectivist approach which discourages individualism and autonomy
- being reluctant to discuss personal and confrontational topics such as health or death-related issues.

Health professionals are cautioned against stereotypical judgments, as there is significant variation within different cultures. SCNs and other health professionals need to be sensitive to individual nuances.³⁹

Resource link

<u>Culture-centred care of people with life-limiting conditions.</u> Palliative Care Curriculum for Undergraduates. Department of Health. 2014

Learning activities		
Completed	Activities	
	Access the following papers and complete the learning activities below:	
	• <u>Issues affecting access to palliative care services for older Chinese people in Australia</u> ⁴⁰ . Hsu, C., Lee, S. & O'Connor, M. (2005)	
	• Approaching death in multicultural Australia ⁴¹ . Lickiss, J.N. (2003)	
	Analyse how aspects of Chinese culture may conflict with underlying principles of a palliative approach to care.	
	2 Discuss how cultural issues are incorporated into a palliative care assessment.	

Case study

Tamsin discusses the transition to palliative care.

Mrs Li's story 6: Culture and end of life care



Learning activities			
Completed			
I		3 Examine factors that would facilitate or hinder the Mrs Li's transition to palliative care.	
I		Discuss strategies which could be used to negotiate optimal outcomes if there is conflict between Mrs Li's and her family's cultural beliefs and principles of a palliative approach to care.	

Supportive care needs during the palliative phase

Nutrition and hydration

Due to the location of head and neck cancer, tumour progression can result in a range of adverse effects impacting all domains of health.

Ensuring adequate nutrition and hydration may present particular challenges, as decisions regarding interventions to supplement nutrition need to be weighed against the personal preferences and burden for the individual.

Learning activities			
Completed			
	Outline the issues which may be considered in an MDT meeting regarding nutritional support for people with advanced head and neck cancer.		
	2 Discuss the ethical considerations in the delivery of parenteral nutrition in palliative care.		

Case study

Mrs Li was readmitted with dehydration and a urinary tract infection. Following a family meeting to consider MDT recommendations, a PEG tube was inserted.

Mrs Li's story 7: nutrition and hydration needs



Learning activities		
Completed	Activities	
	Provide an outline of an education session with Mrs Li and her daughter to manage the PEG tube and its use. Include content for inclusion and evidence-based methods of information provision.	
	As the SCN coordinating Mrs Li's discharge, describe how you would ensure that appropriate, comprehensive information is given to the necessary care providers in the community.	

Clinical emergencies

Carotid blowout, a potential sequelae for individuals with head and neck cancer, is a palliative care emergency. Carotid blowout is considered to be a syndrome with clinical manifestations ranging from acute haemorrhage to asymptomatic exposure of the carotid artery.

Estimated cumulative mortality related to carotid blowout is approximately 40% and major neurologic morbidity is approximately 60%. Radiation therapy (external beam and brachytherapy), radical resection, flap necrosis with carotid exposure, wound infection, pharyngocutaneous fistula, and recurrent or persistent disease have all been implicated as aetiologic factors in carotid blowout syndrome. 42, 43

Medical management options for carotid blowout include:⁴³

- adequate analgesia and sedation
- immediate neck exploration and ligation of the vessels
- endovascular occlusion using detachable balloons or coils
- endovascular stenting of the internal and/or common carotid artery.

Case study

Three months later, Mrs Li is readmitted to hospital with a fungating wound on her neck. Despite her regular PEG feeds at home, Mrs Li has lost weight and looks drawn, tired and cachexic.

Mrs Li's story 8: Emergency readmission



Learning activities		
Completed		Activities
		5 Review the evidence supporting the use of radiotherapy to treat malignant wounds and reduce associated symptoms.
		6 Explain current evidence based principles in the management of the following aspects of fungating wounds:
		managing exudate
		managing odour
		managing bleeding
		wound cleansing
		dressing selection
		managing pain.
		7 Outline strategies for ensuing coordinated care to enable ongoing wound management in the community.

Choice of place of care

The goal of end of life care is to maintain the comfort, choices and quality of life of a person in the terminal phase of their disease. Attention is given to needs across all domains of health, and the person's individual preferences for end of life care need to be central to care planning at this time.⁴⁴ End of life care generally aims to reduce inappropriate and burdensome healthcare interventions to optimise quality of life for all persons.⁴⁴

People vary in their preferences for where they wish to die. Some studies report that over half of people with a progressive illness want to die at home.⁴⁵ In practice, it is important to acknowledge individual differences in preferences for location of death, and also that such preferences may change over time.

Inadequate family support and/or lack of community based palliative care services have been identified as limiting factors for individuals who wish to die at home. 46

Good teamwork and planning ahead, in particular anticipating needs related to symptom control and carer support, may help prevent unwanted hospitalisation when a dying person wants to stay at home. ⁴⁷ Further actions include focusing on the empowerment of families, public education, home based models of care, assessment of risk and training of practitioners in palliative care. ⁴⁶

Learning activity				
Completed	Activity			
	 Access the article Factors influencing death at home in terminally ill patients with cancer: systematic review⁴⁶ Outline factors which influence an individual's place of death. Discuss strategies the SCN may use to promote an individual's death at home if it is preferred. 			

Case study

Discussing parental nutrition.

Mrs Li's story 9: choice of place of care



Learning activities		
Completed		Activities
		Outline your response to Tamsin's concerns regarding caring for her mother at home.
		12 Access the <u>CareSearch webpage – At The End</u> .
		Explain how you could use this information in the development of a discharge plan for Mrs Li's terminal care.
		Identify culturally appropriate services and information you could access in your health care setting and wider community to assist the Li family as they provide palliative care for Mrs Li at home.
		14 If Mrs Li died in hospital before her transfer home, describe how you would ensure respect for cultural beliefs associated with care of her body.
		Describe how you would determine culturally appropriate bereavement support options for Mrs Li's family.

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