

Part 5. General H&N Cancer Supportive Care Problems

Introduction

Although head and neck cancers account for a small percentage of overall cancers, the impact of this disease and its treatment can be devastating. Loss of the ability to share a meal with friends and family, impaired communication or physical disfigurement may result. Successful treatment and rehabilitation depend on a strong interdisciplinary approach, supporting both the patient and significant others. All team members work collaboratively to provide patient education, counseling, support and advocacy. Specific team members are central in helping patients address communication and eating problems that can then have a positive impact on the patient's psychosocial and emotional adjustment and well being.

This document attempts to identify areas of concern for the head and neck cancer patient. These areas are divided into physical, psychosocial, informational and practical domains, with each listing key assessment and care management points. Appendix VI outlines the specific contributions to the care of head and neck cancer patients by the various members of the health care team, Appendix VII provides more detail on the role of Speech Language Pathology and Appendices VIII and IX are resources for community-based providers.

Some District Health Authorities in Nova Scotia have Cancer Patient Navigators who can provide general support and assistance to cancer patients. In those districts where they are available, the Cancer Patient

Navigator is an important supportive care resource who can help patients access all aspects of supportive care. The Cancer Patient Navigator can be reached at 1-866-524-1234 from anywhere in Nova Scotia. As of the time of print, Cancer Patient Navigators are available in South Shore Health, Southwest Health, Annapolis Valley Health, Pictou County Health, and Guysborough, Antigonish, Strait Health Authority (GASHA).

PHYSICAL PROBLEMS

Dysphagia

Dysphagia is a common problem for head and neck cancer patients. Swallowing may be impaired secondary to the disease or as a sequelae of the treatment regimen. Dysphagia can adversely affect treatment tolerance, post-treatment recovery, nutritional status and psychosocial dimensions.

The Capital Health (CH) Head and Neck Cancer Site Team has an active dysphagia team which includes the speech language pathologist, dietitian, nursing staff, and physicians. Other team members may be involved as required. Assessment may include bedside evaluations, modified barium swallows (MBS) and fiberoptic endoscopic evaluations of swallow (FEES) function. The goals of dysphagia management include education and maintaining or establishing safe and efficient oral nutrition and hydration.

Ongoing care management and assessment is individualized and may include:

- Facilitation of patient (and family) understanding of the implications of surgical deficits on swallowing

- Provision of therapeutic swallowing strategies; reinforcement as needed
- Ensuring and teaching adequate oral hygiene
- Supporting and teaching care of the intraoral prostheses
- Training of oral motor exercises
- Development of nutrition care plan
- Provision of diet education for optimization of nutritional status including but not limited to diet texture/nutrient modification and meal planning
- Monitoring of nutrition care plan to ensure patient goals continue to be met
- Implementation and teaching of enteral feeding procedures as needed (see Enteral Nutrition section below)

Nutrition Challenges

Head and neck cancers and their treatment regimens are associated with a multitude of challenges that may impair nutrition status. Many patients are malnourished at the time of diagnosis, while others become nutritionally compromised as a result of intense treatment regimens. Loss of appetite, fatigue, taste changes, dysphagia, odynophagia, xerostomia, mucositis, trismus, social isolation, financial stress, anxiety and excessive use of alcohol may all contribute to reduced nutritional intake. The resulting weight loss and malnutrition may increase morbidity and mortality in head and neck cancer patients.

Ongoing care management and assessment is individualized and may include:

- Development of nutrition care plan

- Provision of diet education for optimization of nutritional status including but not limited to diet texture/nutrient modification and meal planning
- Monitoring of nutrition care plan to ensure patient goals continue to be met
- Implementation and teaching of enteral feeding procedures as needed
- Initiation of appropriate referrals to facilitate access to nutritional supplies (NB. Coverage for the cost of nutritional formula and supplies is an issue for many patients due to inadequate insurance coverage- see Practical Needs, p51)

Enteral Nutrition

Persons with head and neck cancer frequently require enteral nutrition support. Short term post-operative enteral feeding is standard protocol for many resections of the oral cavity, pharynx and laryngopharynx. Some post-operative patients require long-term nutrition support to allow for adequate recovery from cancer treatment, optimal wound healing and swallow function. Chemo/radiation and altered radiation fractionation schedules are being used more frequently to improve disease control but result in greater treatment toxicity. As a result, these patients usually require enteral nutrition support to maintain nutrition and hydration during and post-treatment and therefore, although controversial, it is strongly recommended that prophylactic gastrostomy tube insertion be discussed with patients. Occasionally long-term enteral feeding is required post radiation to manage late term side effects such as dysphagia from tissue fibroses.

Long-term tube feeding presents challenges for patients and their families. The Head and Neck team dietitian works closely with the CH Patient Family Learning Centre and other members of the team to educate, manage, support and advocate for this group of patients. Ongoing care management and assessment is individualized and may include:

- Development of care plan for enteral nutrition to meet estimated nutrition and hydration needs
- Monitoring of nutrition care plan to ensure patient goals continue to be met
- Implementation and teaching of enteral feeding procedures
- Initiation of appropriate referrals to facilitate access to nutritional supplies (NB. Coverage for the cost of nutritional formula and supplies is an issue for many patients due to inadequate insurance coverage- see Practical Needs, p.51)
- Monitoring for adequate hydration/nutrition
- Promoting a positive patient self image and avoidance of social isolation and anxiety (see Psychosocial/Emotional issues p.48).

Respiratory problems

Some patients may develop respiratory problems related to the cancer or subsequent to treatment intervention. A tracheostomy or tracheal stoma may be needed to maintain the airway for some patients.

Ongoing care management and assessment of respiratory problems may include:

- Promotion of secretion clearance
- Stridor and/or airway obstruction

- Teaching of coping strategies to manage respiratory deficiencies
- Reinforcement of safety procedures related to worsening condition, including oxygen saturation monitoring
- Tracheostomy/ tracheal stoma care
 - Implementation and teaching of related tracheal care and ensuring safety
 - Facilitation of access to required supplies (humidifier, ties, etc)
 - Teaching of suctioning procedures and arrange for equipment
 - Initiation of home care referral
 - Initiation of appropriate referrals to support services, (Speech Language Pathology, community support groups, etc.)
- Promoting a positive patient self image and avoidance of social isolation and anxiety (see Psychosocial/Emotional issues p. 48).
- Initiation of appropriate referrals to facilitate access to respiratory supplies. This may be a financial problem for some patients (see Practical Needs, p.51)
- Acknowledge and normalize the fears and anxieties of these problems.

Wound management

Head & neck related wounds may be simple or complex (ranging from a simple incision to a microvascular flap). Management is individualized for each patient. Refer to other guidelines for wound management.

Ongoing care management and assessment of wound healing may include:

- Implementation of appropriate wound care regimen (e.g. flap/graft site)

- Initiation of home care referral
- Facilitation of access to required supplies
- Provision of support strategies to manage potential arterial erosion (see Appendix VIII)

Physical dysfunction problems

Physical dysfunctions, related to immobilization or other treatment-related complications, can occur in this population.

Ongoing care management and assessment of these problems may include:

- Education or provision of range of motion exercises
- Consideration of equipment requirements (e.g. therapeutic bed, walkers, lifts)
- Promotion of general mobility (e.g. transfer practice, walking program)
- Referral to occupational therapy for other Activity of Daily Living (ADL) aids, etc.
- Oral/dental issues (consider referral to community dentist)

Rehabilitation

Selective services may be offered by supportive care/rehabilitative health care professionals for appropriate patients. Some patients may experience a long-term survival from initial therapy with continuing supportive care needs. Physiotherapists, occupational therapists and dietitians may be available through a patient's local District Health Authority and may also be available privately for those with appropriate insurance coverage.

Following discharge from the hospital, speech, voice and/or swallowing treatment will be conducted, as appropriate through the Nova Scotia Hearing and Speech Centres, at the QEII site or through their community centres. Referrals will be forwarded to each community centre as needed. If the patient has had surgical intervention at another facility, physicians or patients should forward the referral to the community Nova Scotia Hearing and Speech Centre. The Centres are located province-wide and can be found in the phone book or online at: www.nshsc.ns.ca.

Within the Capital Health District, referrals should be faxed to the Nova Scotia Hearing and Speech Centre at (902) 473-7313; in Cape Breton (902) 564-7479.

Speech & voice problems

Following non-surgical treatment, voice and speech disorders may be characterized by a reduction in vocal intensity or mild articulation distortions. Following surgical treatment, as the extent of resection (and reconstruction) increases, deficits may be marked by complete loss of voice or speech, adversely affecting communication in social, family or occupational settings.

<i>Ongoing care management and assessment is individualized and may include:</i>

- Facilitation of patient (and family) understanding of the implications of surgical deficits for phonation and articulation.
- Reinforcement and support for interventions that facilitate communication such as the use of electrolarynx, voice prosthesis, communication boards and amplifiers.

- Referral for prosthodontic management for palatal augmentation or obturation.
- Improvement of functional communication either through verbal, written or augmentative/alternative techniques.

For further information, see Appendix VII Speech Language Pathology Services

Hearing

It is common to develop hearing loss (usually Middle Ear or Eustachian tube) following head and neck surgery or with the use of cisplatin chemotherapy (ototoxic). Hearing should be monitored for changes following treatment, surgery or otherwise. If the patient complains of any changes in hearing, he/she should be referred to an audiologist for a hearing test.

Radiation-induced side effects

Radiation therapy to the head and neck can cause mouth changes, skin changes and esophagitis. As these side effects are mostly acute in nature, they are managed within the cancer center at the discretion of the treating Radiation Oncologist. Instructions for any follow up care are provided in the radiation therapy completion note.

Please also see the *CCNS Guidelines for the Management of Oral Complications (2007)*.

Oral Complications from Treatment for Head and Neck Cancers

This section is excerpted from CCNS Best Practice Guidelines for the Management of Oral Complications from Cancer Therapy (2007). For more detail, please refer to the guideline available at www.cancercare.ns.ca or 1-866-599-2267.

Head and Neck cancer patients are at high risk of developing oral complications. 100% of patients receiving radiotherapy to fields involving the oral cavity will experience oral complications. See flowchart (p 44) for the prevention and management of oral complications in Head and Neck cancer patients on radiotherapy.

Problems associated with head and neck radiation include mucositis, infection (local or systemic), salivary gland dysfunction, taste alteration, osteoradionecrosis and pain among others, which result directly or indirectly from the side effects of therapy. These complications can lead to secondary complications such as nutritional disorder, xerostomia or hemorrhage. The nature of these problems and their management is discussed in Chapter 7 of the *Best Practice Guidelines for the Management of Oral Complications from Cancer Therapy*.

Oral complications may be prevented by adherence to a mouth care protocol. Strict oral hygiene procedures and routine use of a mouth rinse solution to prevent development and escalation of oral infection form the basis of good oral care.

Dental assessment and interventions should be addressed prior to the start of radiotherapy. The Capital Health ENT program has an oncology dental program which addresses factors that can predispose a patient for radiotherapy-induced problems. The oncology team, the oral oncology team and the community dentist work together to complete dental work before planned cancer therapy. (Appendix VI page 72).

The *Guidelines for the Management of Oral Complications* **recommends as a best practice** that patients receiving radiotherapy to the oral cavity area should be routinely assessed at every outpatient visit and assessed at least twice during the day shift and once during the night shift for inpatients, using the Mouth Care Record (Appendix IX) in anticipation of oral complications.

Prevention & Management of Oral Complications in H&N Cancer patients

SCREENING

Assess each patient with Mouth Care Record from beginning of treatment until all symptoms are resolved (no longer a focus of care)

Comprehensive dental exam before treatment

- Prosthodontic care prior to radiotherapy to oral cavity
- Eliminate oral disease before treatment (e.g. dental extraction of high-risk dentition) for radiotherapy patients

PREVENTION

<p><u>Prevention- Patients on Radiotherapy</u></p> <ul style="list-style-type: none"> • Topical application of benzydamine solution • Consider use of midline radiation blocks/ 3-D radiotherapy treatment • Do NOT use acyclovir for mucositis prevention • Do NOT use chlorhexidine, sucralfate, acyclovir, or antimicrobial lozenges to prevent mucositis 	<p>Use Intensified Mouth Care Plan: (Table 6.2)</p> <ul style="list-style-type: none"> • Drink plenty of fluids (2L/day) • Oral Fluconazole for prevention of candidiasis <p><u>Follow oral care Recommendations of Dentist</u></p> <ul style="list-style-type: none"> • Dentist may order Chlorhexidine for dental caries prevention when there is no mucositis
<p><u>Patient Education</u> on mouth care and how to manage oral complications from cancer therapy</p>	

MANAGEMENT

Stepped Approach for Management

1. Mucosal coating agent (i.e. attapulgitte [Kaopectate™] antacid suspensions)
 - **Do NOT use Chlorhexidine** if there is mucositis
2. Water-soluble lubricating agents (e.g. artificial saliva, KY Jelly, OraBase)
3. Topical analgesic (i.e. benzydamine)
4. Topical anesthetics (e.g. lidocaine)
 - May use Pain Relief Mouthwash if needed for oral pain (Table 7.4)
5. Systemic opioid analgesics (oral, IV bolus morphine or hydromorphone) for severe pain

Xerostomia Management for Head & Neck Radiotherapy Patients:

- Frequent sips of water
- Oral pilocarpine (5mg BID to TID)
- Ice chips
- Artificial saliva, as tolerated

Oral Hemorrhage:

- Treat with ice water and local pressure

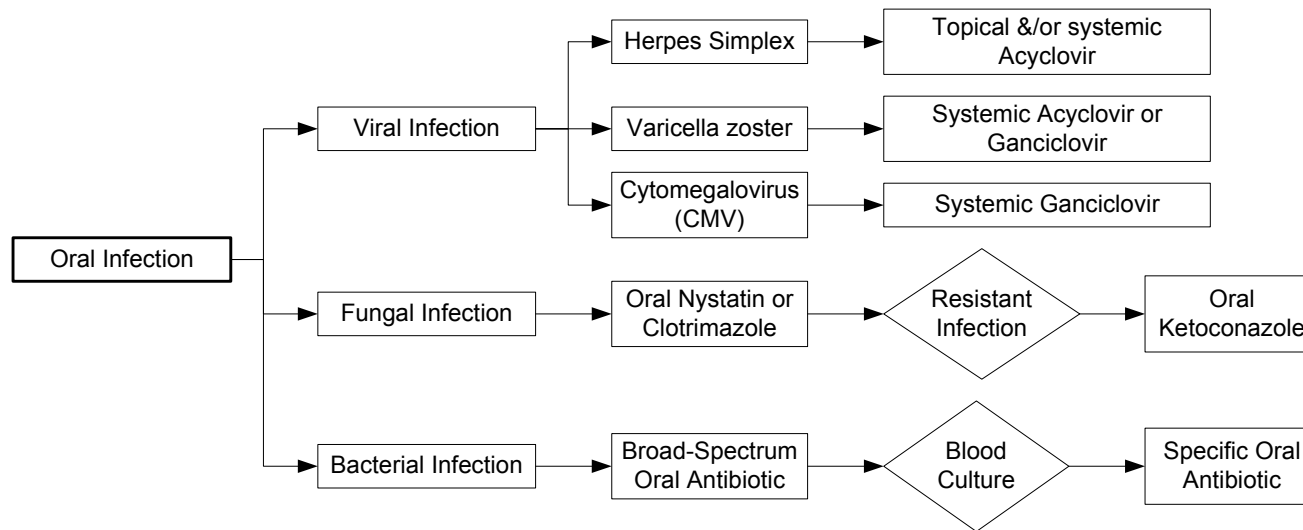
Oral Infection:

- Use appropriate antibiotic
 - For candida use oral Fluconazole (or another azole antifungal agent) for prevention or treatment
 - If Nystatin suspension used for treatment, give this after topical analgesic or anesthetic for treatment of oral fungal infection- Swish and swallow
- See Table 7.6

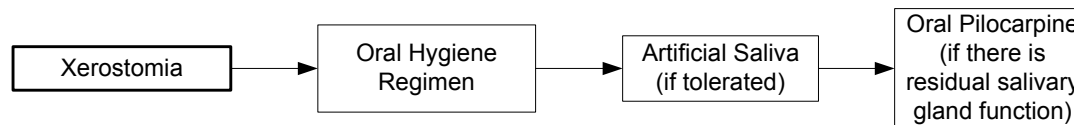
May be duplicated for use in clinical practice. As appears in: Broadfield L, Hamilton J., Best Practice Guidelines for the Management of Oral Complications from Cancer Therapy. © Cancer Care Nova Scotia, 2006

Practice Pathway Management of Specific Oral Complications in Cancer Patients

Oral Infection



Xerostomia

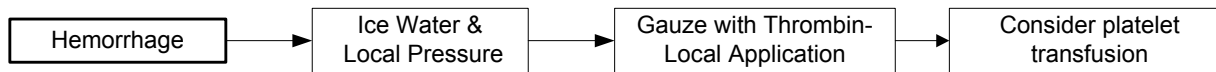


As appears in Cancer Care Nova Scotia guideline Best Practices for the Management of Oral Complications from Cancer Therapy. May be duplicated for use in clinical practice.

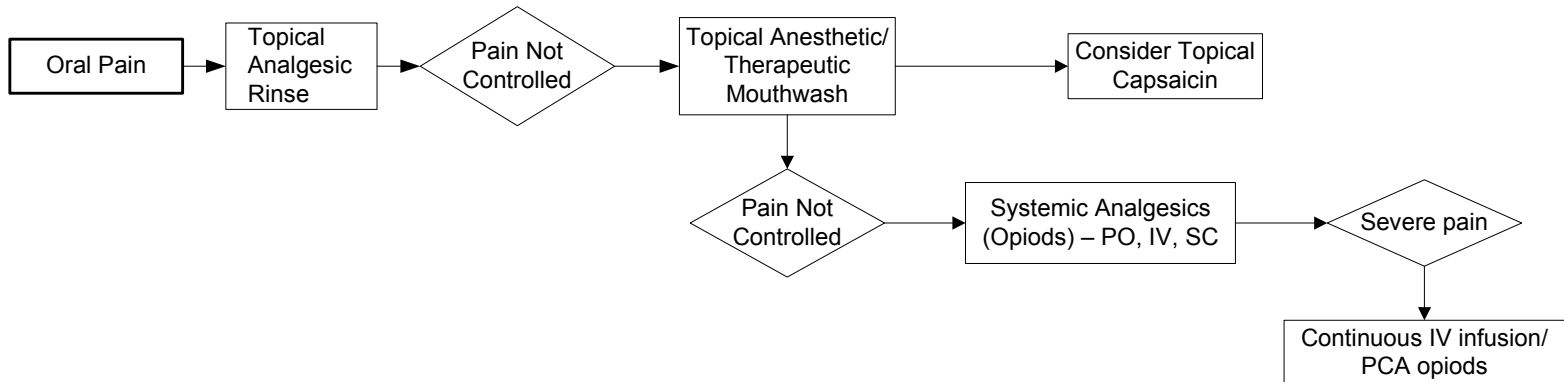
For the full version of this guideline, visit the Cancer Care Nova Scotia website at www.cancercare.ns.ca

Practice Pathway Management of Specific Oral Complications in Cancer Patients

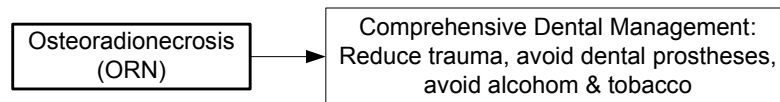
Hemorrhage



Oral Pain



Osteoradionecrosis (ORN)



As appears in Cancer Care Nova Scotia guideline Best Practices for the Management of Oral Complications from Cancer Therapy. May be duplicated for use in clinical practice. For the full version of this guideline, visit the Cancer Care Nova Scotia website at www.cancercare.ns.ca

Pain and Symptom Management

A number of resources exist for patients who need help with pain or symptom management and/or palliative care. These include the attending oncology team, the Cancer Patient Navigator, and the local palliative care team as well as the following CCNS guidelines:

- *Best Practice Guidelines for the Management of Oral Complications from Cancer Therapy (2007)*
- *Guidelines for the Management of Cancer-related pain (2006)*
- *Guidelines for the Management of Nausea and Vomiting in Cancer Patients (2004)*

These are available in Adobe Reader version on the CCNS website (www.cancercare.ns.ca). Hard copies are available upon request at Info@ccns.nshealth.ca or 1-866-599-2267.

In Chapter 7 of the *Guidelines for the Management of Oral Complications*, there is a best practice statement for the management of oral pain. Patients who experience oral pain, alone or in combination with other oral complications, may be treated with coating suspensions, topical analgesic solutions, topical anesthetics or pain relief mouthwash suspensions, and systemic analgesics (for increasing severity of the pain). Clinicians should only use the institutional standard(s) for pain relief mouthwash formulations. (See flowchart on p 46 of this guideline).

Referral Information for the District Palliative Care/ Supportive Care Services:

Palliative Care Teams in Nova Scotia

South Shore Health:

902-634-7369 or 902-354-3436

South West Health

902-742-3542 ext 414

Annapolis Valley Health

902-678-7381 ext 2270

Colchester East Hants Health Authority

902-893-5554 ext 2306

Cumberland Health Authority

902-667-5400 ext 6373

Pictou County Health

902-752-7600 ext 4190

Guysborough Antigonish Strait Health Authority

902-867-4296 or 902-867-4436

Cape Breton District Health Authority

902-567-7846

Capital Health

902-473-3119

PSYCHOSOCIAL/EMOTIONAL (See Practice Pathway p.50)

Unique psychosocial problems

Head and neck cancer patients deal with significant psychosocial and emotional adjustments, stresses, and losses during their cancer experience. Many individual factors (e.g., coping style and resources, fears, nature of cancer diagnosis and medical treatment, supports) can affect the patient's ability to cope with his/her illness and its sequelae. Emotional and psychosocial difficulties displayed by head and neck cancer patients and their family members can occur throughout the cancer care continuum. Some of the difficulties that these patients may experience include the following:

- Emotional distress (e.g., depression, anxiety, fear of cancer recurrence, living with uncertainty of cancer and life-threat).
- Fear of being rejected
- Fear of choking, suffocating
- Communication difficulties
- Eating problems.
- Difficulties with body image, disfigurement, lowered self-esteem and social withdrawal/isolation
- Dealing with lifestyle adjustments and losses (e.g., vocational changes such as being on disability, loss of work, work changes; changes in avocational activities; role changes in family; reduced functioning).
- Addiction or use/abuse of alcohol and tobacco and other substances
- Pain management problems.
- Difficulty managing stress.
- Interpersonal issues.

- Couple and family difficulties.
- Sexual issues (loss of touching, intimacy)
- Difficulties adhering to treatment
- Financial stress
- Pre-existing difficulties exacerbated by illness experience.
- Dealing with death and dying.

Ongoing management of psychosocial and emotional difficulties includes the following:

- Provision of psychosocial support and encouragement.
- Encouraging patients to use their coping/stress management strategies that are helpful, if possible.
- Helping patients access positive social supports.
- Encouraging patients to focus on whole-person approach to coping with illness (e.g. physical, psychological, social, spiritual).
- Referring patients to psychosocial oncology healthcare professionals (e.g. psychologists, psychiatrists, social workers, spiritual care workers, advanced practice nurses) and other specialized services such as Addictions Services for consultation and treatment (e.g., psycho-education, counseling, and psychotherapy, as appropriate).
- Encouraging patient involvement in relevant support groups, if appropriate
- Counseling and support for addiction and abuse through referrals to Addiction Services and interventions to manage withdrawal of substances such as alcohol, nicotine, etc.

Cognitive problems

Ongoing management and assessment of problems related to:

- Acute problems during treatment (eg. surgery, radiation, chemo)
- Confusion/Delirium Tremors
 - Medicate as ordered
 - Continually orient to person/place/time
 - Ensure safety at all times
- Concentration and Memory Difficulties related to emotional distress and stress and/or dementia, organic brain syndrome etc.
- Referral to psychosocial oncology healthcare professional for consultation and treatment, as appropriate.
- Referral to Speech-Language Pathologist for assessment and management of communication issues related to dementia or organic brain syndrome.

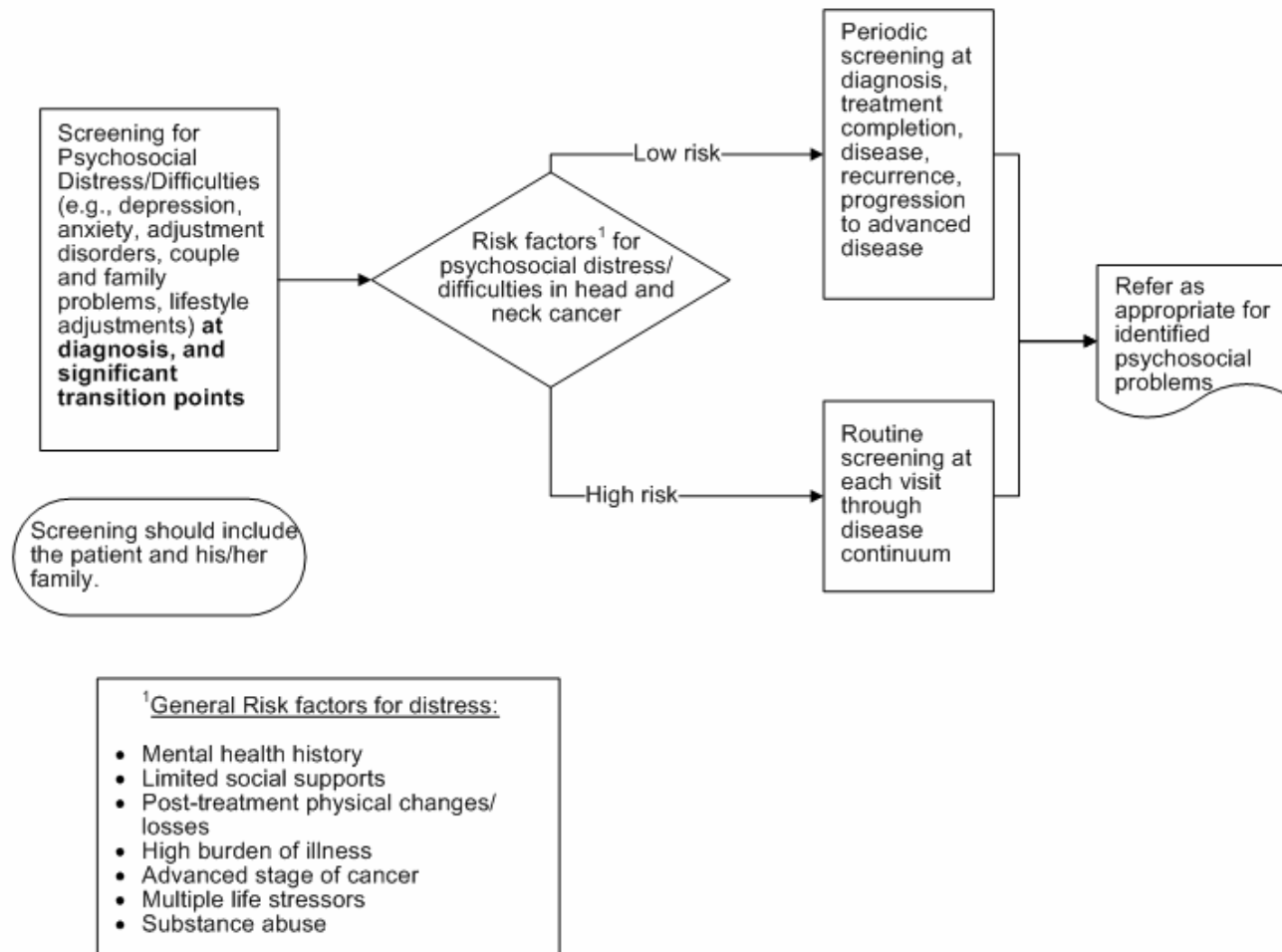
INFORMATION RESOURCES FOR PATIENTS/FAMILIES

It is important that these patients receive information as soon as possible. For some patients, information may need to be discussed before they lose verbal communication (e.g. post-laryngectomy).

In addition to information that health professionals provide to their patients, there are other information sources that Head and Neck cancer patients may find useful:

- **Oncology Interactive Education Series (OIES).** This interactive CD-ROM series includes a head and neck cancer-specific disk. This disk is available to head and neck patients at the Head and Neck clinic at the Nova Scotia Cancer Centre and is also available in all regional hospitals (the surgical pre-operative clinics or chemotherapy clinics) in Nova Scotia, the two cancer centres and the Lodge that Gives in Halifax. Patients can also access this service through a Cancer Patient Navigator.
- The Canadian Cancer Society's Information Service is a national, bilingual, toll-free service offering comprehensive information about head and neck cancers and cancer in general as well as community resources to cancer patients, their families, the general public and healthcare professionals. 1-888-939-3333 or www.cancer.ca

Practice Pathway for the Management of Psychosocial Issues in Head and Neck Cancers



In addition to general support resources (e.g. Canadian Cancer Society, Cancer Patient Navigators, palliative care services), those of particular use to head and neck cancer patients include the following. Listings for these and other resources locally, provincially and nationally can be obtained through

- the Canadian Cancer Society's Information Service (above):
- Laryngectomy Society of Nova Scotia
- Facial disfigurement support groups- About Face
- Wig Retailers
- Peer Visitation (programs and informal arrangements)
- Department of Veterans Affairs
- Provincial/Municipal Income Assistance Programs
- Insurance Companies
- Home O₂/Respiratory Therapy equipment suppliers
- Sunshine Room QEII HSC (and similar cancer patient support rooms in other sites)
- "Look Good- Feel Better" program
- QEII Patient and Family Learning Centre and the Cape Breton Cancer Centre Paul J. Veinotte Memorial Library.

PRACTICAL

Cancer patients are frequently challenged by practical issues such as lack of transportation, especially to a tertiary centre, and financial barriers including access to drugs, nutritional formula and supplies due to lack of insurance coverage as well as loss of income due to illness. Health professionals should assess patients for areas of practical concern. Cancer Patient Navigators and the Canadian Cancer Society may be able to provide assistance for those in need or referrals to other agencies.

Other practical issues faced by head and neck cancer patients may include:

- ♦ Discharge planning issues
- ♦ Lack of availability of nutritional formula and supplies or inability to purchase due to low income and inadequate or non-existent insurance coverage.
 - Increasing needs related to changes in disease management practices
 - Financial impact to patients and families
- ♦ Lack of availability of home care nursing, community nursing, care giving services
- ♦ Additional resources that may be required by head and neck cancer patients include (may be paid by patient or private insurance- incomplete coverage by public insurers):
 - Speech devices
 - Humidification devices
 - Tracheal stoma supplies
 - Enteral feeding supplies & equipment
 - Oral and prosthetic supplies
- ♦ General dental care and maintenance is not covered under MSI, although cancer treatments (especially radiation therapy) can have a significant effect on a patient's dentition. Costs for these services are the

responsibility of the patient through their own means or through private dental insurance. These services are provided by the patient's own community dentist. Unfortunately, many patients are unable to afford proper dental care. There is coverage for oncologic dental prosthesis under MSI for Nova Scotia residents through the cancer team's Maxillofacial Prosthodontist. Coverage for patients from other provinces must be arranged in advance, and may not be available.

- ◆ Other psychological or supportive care services (e.g. counseling, psychotherapy, nutrition counselling, physiotherapy, etc.) for ambulatory patients may be on a fee-for-service basis, and may not be covered by insurance plans.