



# AMERICAN CANCER SOCIETY HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY

Assessment and Management of Long-term and Late Effects



## MUSCULOSKELETAL AND NEUROMUSCULAR

- Assess for spinal accessory nerve palsy (U) and refer to rehabilitation specialist to improve range of motion and ability to perform daily tasks, with more complex clinical situations referred to a Physical Medicine and Rehabilitation physician for expert assessment
- Assess for cervical dystonia (U) and refer for comprehensive neuromusculoskeletal management if cervical dystonia or neuropathy (U) found
- Prescribe nerve stabilizing agents such as pregabalin, gabapentin and duloxetine or refer to a specialist for botulinum toxin type A injections into the affected muscles for pain management and spasm control as indicated
- Assess for shoulder pain and dysfunction (H) after neck dissection
- Conduct baseline assessment of shoulder function post treatment and continue to assess for emerging pain or functional impairment, referring to rehabilitation specialist for improvement to pain, disability and range of motion
- Refer to rehabilitation specialists and dental professionals to prevent and treat trismus (M) and prescribe nerve stabilizing agents to combat pain and spasms as indicated



## SWALLOWING

- Assess for complaints of dysphagia (U), postprandial cough, unexplained weight loss and/or pneumonia and refer to an experienced rehabilitation specialist for instrumental evaluation of swallowing function to assess and manage dysphagia and possible aspiration (U)
- Refer to appropriate clinician as needed to address psychosocial barriers to swallowing recovery
- Refer to speech language pathologist for videofluoroscopy as the first line test for suspected stricture (L M) due to high degree of coexisting physiologic dysphagia
- Refer to gastroenterologist or head and neck surgeon for esophageal dilation in cases of stricture



## HEARING LOSS, VERTIGO VESTIBULAR NEUROPATHY

- Assess for loss of hearing (U), vertigo (U) or vestibular neuropathy (U) and refer to appropriate specialists
- Evaluate survivors with history of ototoxic drug exposure for chronic, potentially progressive sensorineural hearing loss



## REFLUX

- Monitor for developing or worsening gastroesophageal reflux disease
- Counsel on increased risk of esophageal cancer and associated symptoms
- Recommend proton pump inhibitors or antacids, sleeping with a wedge pillow or 3 inch blocks under head of bed, not eating or drinking three hours before bed, tobacco cessation and alcohol avoidance
- Refer to gastroenterologist if symptoms are not relieved by these treatments



## LYMPHEDEMA

- Assess for lymphedema (H) using NCI's Common Terminology Criteria for Adverse Events v. 4.03 or refer for endoscopic evaluation of mucosal edema of the oropharynx and larynx, tape measurements, sonography or external photographs
- Refer to a rehabilitation specialist for treatment consisting of manual lymphatic drainage and, if tolerated, compressive bandaging



## FATIGUE

- Assess for fatigue (U) and treat any causative factors (e.g., anemia, thyroid or cardiac dysfunction)
- Offer treatment or referral for factors that may impact fatigue (e.g., mood disorders, sleep disturbance, pain)
- Counsel survivors to engage in regular physical activity and refer for cognitive behavioral therapy as appropriate



## TASTE

- Assess for altered or loss of taste (U)
- Refer to a registered dietitian for dietary counseling and assistance in additional seasoning of food, avoiding unpleasant food and expanding dietary options



## THYROID

- Assess for hypothyroidism (L H)
- Evaluate thyroid function by measuring thyroid stimulating hormone levels every 6-12 months

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

# AMERICAN CANCER SOCIETY HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)

## Assessment and Management of Long-term and Late Effects



### SLEEP DISTURBANCE/APNEA

- Screen for sleep disturbance (U) by asking survivors and partners about snoring and symptoms of sleep apnea (U)
- Refer to sleep specialist for a sleep study if sleep apnea is suspected
- Manage sleep disturbance similar to patients in the general population
- Recommend nasal decongestants, nasal strips, cool mist humidifiers and sleeping in a propped up position to reduce snoring and mouth breathing
- Refer to dental professional to test fit of dentures, counsel to remove dentures at night to avoid irritation



### SPEECH/VOICE

- Assess for speech disturbance (U)
- Refer to experienced speech language pathologist specialist if communication disorder exists
- Radiation associated lower cranial neuropathies (L) may cause delayed speech or voice deterioration in long term survivors



### BODY AND SELF IMAGE

- Assess for body (H) and self image concerns
- Refer for psychosocial care as indicated



### DISTRESS, DEPRESSION AND ANXIETY

- Assess for distress (H), depression (L H) and/or anxiety (L) periodically (3 months post treatment and at least annually) using a validated screening tool
- Offer in office counseling and/or pharmacotherapy and/or refer to appropriate psycho oncology and mental health resources as clinically indicated if signs of distress, depression or anxiety are present
- Refer to mental health specialists for specific quality of life concerns, such as social workers for issues like financial and employment challenges or addiction specialists for substance abuse

### DENTAL/ORAL



- Counsel close follow up with dental professional and reiterate that proper preventive care can help reduce caries (U) and gingival disease
- Counsel to avoid tobacco, alcohol (including mouthwash containing alcohol), spicy or abrasive foods, extreme temperature liquids, sugar containing chewing gum or sugary soft drinks and acidic or citric liquids
- Refer to dental professional specializing in the care of oncology patients
- Assess for periodontitis (U) and refer to a dentist or periodontist for thorough evaluation
- Counsel regular examination of the gingival attachment as normal part of ongoing dental care
- Assess for xerostomia (U) and counsel use of alcohol free mouth rinses, consuming a low sucrose diet and avoiding caffeine, spicy and highly acidic foods and tobacco
- Avoid dehydration by drinking fluoridated tap water but explain that consumption of water will not eliminate xerostomia
- Monitor for swelling of jaw and/or jaw pain indicating possible osteonecrosis (U)
- Administer conservative treatment protocols such as broad spectrum antibiotics and daily saline or aqueous chlorhexidine gluconate irrigations for early stage lesions
- Refer to head and neck surgeon for consideration of hyperbaric oxygen therapy for early and intermediate lesions, for debridement of necrotic bone while undergoing conservative management or for external mandible bony exposure through the skin
- Assess for oral infections/candidiasis (L) and refer to qualified dental professional for treatment and management of complex oral conditions and infections
- Consider systemic fluconazole and/or localized therapy of clotrimazole troches to treat oral fungal infections
- Higher risk criteria:
  - Poor dental care
  - Comorbid states (e.g., autoimmune diseases, poor nutritional status, diabetes, alcohol abuse, tobacco use and poor general health status)
  - Those treated with radiation or chemotherapy and experiencing long term xerostomia as a result, or loss of gingival attachment
  - Xerostomia inducing medications (e.g., anticholinergics, antihypertensives, antihistamines, neurology and nervous system drugs and decongestants)
  - Those who experience surgical ablation of the salivary glands or associated ducts
  - Radiation therapy to oral cavity and salivary glands increases risk of osteonecrosis

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

# AMERICAN CANCER SOCIETY HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)



## SURVEILLANCE AND SCREENING

- Individualize clinical follow up care based on age, specific diagnosis and treatment
- Conduct detailed cancer related history and physical exam according to schedule based on risk:
  - Every 1-3 months for the first year after primary treatment
  - Every 2-6 months for the second year
  - Every 4-8 months for years 3-5
  - Annually after 5 years
- Confirm continued follow up with otolaryngologist or HNC specialist for HN focused exam
- Educate about signs and symptoms of local recurrence and refer to HNC specialist if signs and symptoms of local recurrence present
- Screen for lung cancer according to ASCO or NCCN recommendations for annual lung cancer screening with LDCT for high risk patients based on smoking history
- Screen for other head and neck and esophageal cancer as would for patients of increased risk
- Screen for other cancers as in general population according to [American Cancer Society screening and early detection guidelines](#)



## HEALTH PROMOTION

- Assess information needs related to HNC and its treatment, side effects, other health concerns and available support services and provide or refer to appropriate resources
- Counsel survivors to achieve and maintain a healthy weight; weight management is considered a priority standard of care
- Counsel survivors on nutrition strategies to maintain a healthy weight for those at risk of cachexia
- If overweight or obese, counsel to limit consumption of high calorie foods and beverages
- Counsel survivors to engage in regular physical activity including:
  - Aerobic exercise at least 150 minutes per week
  - Strength training exercise at least 2 days per week
- Counsel survivors to achieve a dietary pattern that is high in vegetables, fruits and whole grains, low in saturated fats and sufficient in dietary fiber
- Assess for nutrition related challenges and refer to a registered dietitian or specialist
- Assess for tobacco use and offer and/or refer survivors to cessation counseling and resources and counsel survivors to avoid tobacco products
- Counsel survivors to avoid alcohol consumption
- Counsel survivors to maintain regular dental care including frequent visits to dental professionals, early interventions for dental complications and meticulous oral hygiene



## CARE COORDINATION

- Consult with cancer treatment team and request a treatment summary and survivorship care plan
- Maintain communication with cancer treatment team throughout diagnosis, treatment and post treatment care to ensure care is evidence based and well coordinated
- Refer to dentist to provide diagnosis and treatment of dental caries, periodontal disease and other intraoral conditions including mucositis and oral infections, and communicate with dentist on follow up recommendations and patient education
- Coordinate care with other medical specialists to address comorbidities, symptoms and effects
- Encourage inclusion of caregivers, spouses or partners in usual HNC survivorship care and support

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

View full-text guideline at [bit.ly/acshadneck](https://bit.ly/acshadneck)

# HEAD AND NECK CANCER SURVIVORSHIP CARE: LONG-TERM AND LATE EFFECTS SUMMARY

<b>Long-term Effects</b> Start during treatment and persist	<b>Late Effects</b> Start after treatment ends	
<b>Surgery Effects (Neck Dissection, Laryngectomy)</b>		
<b>Shoulder function</b> <ul style="list-style-type: none"> <li>• Shoulder mobility, pain</li> </ul> <b>Oral health complications</b> <ul style="list-style-type: none"> <li>• Xerostomia</li> <li>• Dysphagia</li> <li>• Oral infections</li> </ul> <b>Musculoskeletal effects</b> <ul style="list-style-type: none"> <li>• Trismus</li> <li>• Impaired neck motion, pain</li> <li>• Stricture</li> </ul>	<ul style="list-style-type: none"> <li>• Spinal nerve abnormalities</li> <li>• Lymphedema</li> <li>• Neuropathy</li> <li>• Cervical radiculopathy</li> </ul>	
<b>Radiation Therapy Effects (IMRT, Mediastinal RT)</b>		
<b>Oropharyngeal</b> <ul style="list-style-type: none"> <li>• Xerostomia</li> <li>• Dysphagia</li> </ul> <b>Neuromuscular</b> <ul style="list-style-type: none"> <li>• Cervical dystonia</li> <li>• Trismus</li> </ul> <b>Musculoskeletal</b> <ul style="list-style-type: none"> <li>• Shoulder dysfunction</li> </ul> <b>Integumentary</b> <ul style="list-style-type: none"> <li>• Radiation dermatitis</li> </ul> <b>Lymphovascular</b> <ul style="list-style-type: none"> <li>• Lymphedema</li> </ul> <b>Oral health complications</b> <ul style="list-style-type: none"> <li>• Xerostomia</li> <li>• Oral infections</li> </ul>	<b>Vision</b> <ul style="list-style-type: none"> <li>• Premature cataracts</li> </ul> <b>Cardiovascular</b> <ul style="list-style-type: none"> <li>• Carotid obstruction</li> <li>• Baroreceptor failure</li> </ul> <b>Oropharyngeal</b> <ul style="list-style-type: none"> <li>• Xerostomia</li> <li>• Dysphagia</li> <li>• Dysarthria</li> </ul> <b>Pulmonary</b> <ul style="list-style-type: none"> <li>• Pulmonary fibrosis</li> </ul> <b>Neuromuscular</b> <ul style="list-style-type: none"> <li>• Cervical dystonia</li> <li>• Trismus</li> <li>• Brachial plexopathy</li> <li>• Cervical radiculopathy</li> </ul>	<b>Musculoskeletal</b> <ul style="list-style-type: none"> <li>• Osteonecrosis</li> </ul> <b>Lymphovascular</b> <ul style="list-style-type: none"> <li>• Lymphedema</li> </ul> <ul style="list-style-type: none"> <li>• Carotid stenosis</li> </ul> <b>Sensory complications</b> <ul style="list-style-type: none"> <li>• Hearing loss</li> <li>• Ocular issues</li> <li>• Altered or loss of taste</li> </ul>
<b>Chemotherapy Effects</b>		
<b>Neuromuscular</b> <ul style="list-style-type: none"> <li>• Sensor/motor neuropathy</li> <li>• Sensory ataxia</li> <li>• Gait dysfunction</li> <li>• Vertigo</li> </ul> <b>Other effects</b> <ul style="list-style-type: none"> <li>• Hot flashes/sweats</li> <li>• Weight gain, abdominal obesity</li> <li>• Fatigue/decreased activity</li> <li>• Anemia</li> <li>• Body hair loss</li> <li>• Dry eyes</li> </ul>	<b>Neuromuscular</b> <ul style="list-style-type: none"> <li>• Cardiac abnormality, cardiomyopathy</li> </ul> <b>Other effects</b> <ul style="list-style-type: none"> <li>• Osteoporosis, fractures</li> <li>• Metabolic syndrome</li> <li>• Cardiovascular disease—possible increased risk of myocardial infarction</li> <li>• Diabetes; decreased sensitivity to insulin and oral glycemic agents</li> <li>• Increased cholesterol</li> <li>• Increased fat mass and decreased lean muscle mass/muscle wasting</li> <li>• Venous thromboembolism</li> <li>• Vertigo</li> <li>• Cognitive dysfunction</li> </ul>	

### General Psychological Long term and Late Effects

- Depression
- Distress—multifactorial unpleasant experience of psychological, social, and/or spiritual nature
- Worry, anxiety
- Fear of recurrence
- Pain-related concerns
- End-of-life concerns: Death and dying
- Changes in sexual function and/or desire
- Challenges with body image (secondary to surgery, laryngectomy, radiation)
- Challenges with self-image
- Relationship and other social role difficulties
- Return-to-work concerns and financial challenges

### More Information

View the American Cancer Society Head and Neck Cancer Survivorship Care Guideline at: [bit.ly/acsheadneck](https://bit.ly/acsheadneck)

# HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE CHECKLIST FOR PROVIDERS

Clinical follow-up care provided to head and neck cancer survivors should be individualized based on age, specific diagnosis and treatment protocol.

## Surveillance

- Conduct detailed cancer-related history and physical exam according to schedule based on risk:
  - Every 1-3 months for the first year after primary treatment
  - Every 2-6 months for the second year
  - Every 4-8 months for years 3-5
  - Annually after 5 years
- Confirm continued follow-up with otolaryngologist or HNC specialist for HN-focused exam.
- Educate about signs and symptoms of local recurrence and refer to HNC specialist if signs and symptoms of local recurrence present.

## Screening for Second Primary Cancers

- Screen head and neck cancer survivors for other cancers as for patients in the general population according to [ACS Early Detection Recommendations](#).
- Screen head and neck cancer survivors for lung cancer according to ASCO or NCCN recommendations for annual lung cancer screening with low-dose CT for high-risk patients based on smoking history.
- Screen for other head and neck and esophageal cancer as for patients with increased risk.

## Assessment and Management of Physical and Psychological Effects

- Discuss musculoskeletal and neuromuscular effects, including **spinal accessory nerve palsy, cervical dystonia, muscle spasms, neuropathies, shoulder dysfunction and trismus**. Refer to rehabilitation specialists, dental professionals or more complex clinical situations to a physical medicine and rehabilitation physician for expert assessment.
- Assess for **dysphagia, postrandial cough, unexplained weight loss** and/or **pneumonia** and refer to an experienced speech-language pathologist for instrumental evaluation of swallowing function to assess and manage **dysphagia** and possible **aspiration**. Refer to appropriate clinician as needed to address psychosocial barriers to swallowing recovery. Refer to speech-language pathologist for videofluoroscopy as the first-line test for suspected **stricture** due to high degree of coexisting physiologic dysphagia. Refer to gastroenterologist or head and neck surgeon for esophageal dilation in cases of stricture.
- Monitor for developing or worsening **gastroesophageal reflux disease**. Counsel on increased risk of **esophageal cancer** and associated symptoms. Recommend proton pump inhibitors or antacids, sleeping with wedge pillow or three-inch blocks under head of bed, not eating or drinking three hours before bedtime, tobacco cessation and alcohol avoidance. Refer to gastroenterologist if symptoms are not relieved by these treatments.

- Assess for **lymphedema** using NCI's Common Terminology Criteria for Adverse Events v. 4.03 or refer for endoscopic evaluation of **mucosal edema** of the oropharynx and larynx, tape measurements, sonography or external photograph. Refer to a rehabilitation specialist for treatment consisting of manual lymphatic drainage and, if tolerated, compressive bandaging.
- Assess for **fatigue** and treat any causative factors (e.g., anemia, thyroid or cardiac dysfunction). Offer treatment or referral for factors that may impact fatigue (e.g., mood disorders, sleep disturbance, pain). Counsel survivors to engage in regular physical activity and refer for cognitive behavioral therapy as appropriate.
- Discuss **altered or loss of taste**. Refer to a registered dietitian for dietary counseling and assistance in additional seasoning of food, avoiding unpleasant food and expanding dietary options.
- Assess for **hearing loss, vertigo** and **vestibular neuropathy**. Refer to appropriate specialists as needed.
- Screen for **sleep disturbance** by asking survivors and partners about **snoring** and symptoms of **sleep apnea**. Refer survivors to a sleep specialist for a sleep study if sleep apnea is suspected. Manage sleep disturbance similar to patients in the general population. Recommend nasal decongestants, nasal strips, cool mist humidifiers and sleeping in the propped-up position to reduce snoring and mouth-breathing. Refer to a dental professional to test the fit of dentures and counsel to remove dentures at night to avoid irritation.
- Assess for **speech disturbance** and refer to experienced speech-language pathologist specialist if communication disorder exists.
- Evaluate thyroid function and assess for **hypothyroidism** by measuring thyroid stimulating hormone levels every 6-12 months.
- Counsel close follow-up with dental professional and reiterate that proper preventive care can help reduce **caries** and **gingival disease**. Counsel to avoid tobacco, alcohol (including mouthwash containing alcohol), spicy or abrasive foods, extreme temperature liquids, sugar-containing chewing gum or sugary soft drinks and acidic or citric liquids. Refer to a dental professional specializing in the care of oncology patients.
- Assess for **periodontitis** and refer to a dentist or periodontist for thorough evaluation. Counsel to seek regular treatment from and follow recommendations of a qualified dental professional and reinforce proper examination of the gingival attachment is a normal part of ongoing dental care.
- Assess for **xerostomia** and counsel to use alcohol-free mouth rinses, consume a low-sucrose diet, avoid caffeine, spicy and highly acidic foods and tobacco. Counsel to avoid dehydration by drinking fluoridated tap water, but explain that consumption of water will not eliminate **xerostomia**.
- Monitor for swelling of the jaw and/or jaw pain indicating possible **osteonecrosis**. Administer conservative treatment protocols such as broad-spectrum antibiotics and daily saline or aqueous chlorhexidine gluconate irrigations for early-stage lesions. Refer to a head and neck surgeon for consideration of hyperbaric oxygen therapy for early and intermediate lesions, for debridement of necrotic bone while undergoing conservative management, or for external mandible bony exposure through the skin.
- Assess for **oral infections/candidiasis**. Refer to qualified dental professional for treatment and management of complicated oral conditions and infections. Consider

systemic fluconazole and/or localized therapy of clotrimazole troches to treat **oral fungal infections**.

- Assess for body and self-image concerns and refer for psychosocial care as indicated.
- Assess for **distress/depression** and/or **anxiety** three months post treatment and at least annually using a simple screening tool, such as the [Distress Thermometer](#). Manage **distress/depression/anxiety** using in-office counseling resources or pharmacotherapy as appropriate. Refer survivors experiencing **distress/depression/anxiety** for further evaluation and/or treatment by appropriate specialists if needed. Refer to mental health specialists for specific quality of life concerns, such as social workers for issues like financial and employment challenges or addiction specialists for substance abuse.

Assessment Tools			
<a href="#">Center for Epidemiological Studies Depression Scale (CES-D)</a>	<a href="#">Generalized Anxiety Disorder (GAD)-7</a>	<a href="#">Distress Thermometer</a>	<a href="#">Patient Health Questionnaire (PHQ)-9</a>

### Health Promotion

- Assess information needs related to head and neck cancer and its treatment, side effects, other health concerns and available support services. Provide or refer to appropriate resources to meet these needs.
- Counsel to achieve and maintain healthy weight by limiting consumption of high-calorie foods and beverages and promoting increased physical activity.
- Counsel survivors on nutrition strategies to maintain a healthy weight for those at risk for cachexia.
- Counsel to engage in at least 150 minutes per week of physical activity; this may include weight-bearing exercises.
- Counsel to achieve a dietary pattern high in vegetables, fruits and whole grains.
- Counsel survivors if overweight or obese to limit consumption of high-calorie foods and beverages and increase physical activity to promote and maintain weight loss. Head and neck cancer survivors often experience significant, highly visible facial disfigurement and notable treatment-induced problems with eating, swallowing and breathing. Survivors may also experience loss of taste and smell, excessive dry mouth and other deficits of functioning in the oral cavity including negatively impacting the ability to eat. As a result, survivors may have difficulty gaining and maintaining a healthy weight. Avoiding wasting should be a primary aim of health promotion with these patients. Refer to registered dietician to address nutrition-related challenges.
- Counsel to avoid alcohol consumption.
- Assess for tobacco use and offer and/or refer to cessation counseling and resources. Counsel to avoid tobacco products.
- Counsel to maintain regular dental care including frequent visits to dental professionals, early interventions for dental complications and meticulous oral hygiene. Test dentures to ensure proper fit, and counsel to remove them at night to avoid irritation. Counsel that nasal strips can reduce snoring and mouth-breathing and that room humidifiers and nasal saline sprays can aid sleep as well.



- Train survivors to do at-home head and neck self-evaluations and instruct survivors to report any suspicions or concerns immediately.

### Care Coordination

- Consult with cancer treatment team and obtain a treatment summary and survivorship care plan.
- Maintain communication with oncology team throughout diagnosis, treatment and post-treatment care to ensure care is evidence-based and well-coordinated.
- Refer to dentist to provide diagnosis and treatment of dental **caries**, **periodontal disease** and other intraoral conditions including **mucoisitis** and **oral infections** and communicate with dentist on follow-up recommendations and patient education.
- Encourage inclusion of caregivers, spouses, or partners in usual head and neck cancer survivorship care.

View the American Cancer Society Head and Neck Cancer Survivorship Care Guideline at: [bit.ly/acsheadneck](https://bit.ly/acsheadneck)