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SALIVARY GLAND
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SINUS & NASAL
THROAT

6th Edition

HEAD & NECK CANCER

A TREATMENT GUIDE FOR PATIENTS AND THEIR FAMILIES

CONTENT REVIEWED BY A DISTINGUISHED MEDICAL ADVISORY BOARD

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6th Edition

HEAD & NECK CANCER

IN THIS GUIDE

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Empower yourself with crucial information

Head and neck cancer collectively describes a variety of malignant tumors that affect the mouth, pharynx (throat), larynx (voice box), sinuses, nose, thyroid and salivary glands. Because these areas of the body are involved with appearance and vital functions, such as breathing, eating and speaking, a head and neck cancer diagnosis often affects many areas of life. Learn as much as possible about your diagnosis so you can be confident making the important decisions ahead.

This guide will provide you with information about the types of head and neck cancer, staging, treatments, support services and more. Becoming an informed patient will help you communicate better with your medical team. If there is something you do not understand, ask for an explanation.

It is important to realize that treating your head and neck cancer may be a lengthy process. It is more than removing a tumor and killing cancer cells. It also includes repairing areas that may be damaged by treatment to preserve and restore normal function as much as possible.

DIAGNOSING & STAGING

Determining the type of cancer you have and the extent of it will be the first goal of your physician. A variety of tests may be used, including a physical exam, imaging studies, blood tests and a biopsy. Your doctor will be looking for where the tumor is, how large it is, whether it has spread to lymph nodes or other organs, any biomarkers and the type or subtype of the cancer.

Once a diagnosis is made, your doctor will classify and stage the cancer according to the TNM system developed by the American Joint Committee on Cancer (AJCC). This system classifies the cancer by tumor (T), node (N) and metastasis (M). The T category describes the size and location of the primary tumor. The N category indicates whether the lymph nodes show evidence of cancer cells. The number and location of these lymph nodes are important because they show how far the disease has spread. The M category describes metastasis (spread of cancer to another part of the body), if any.

Staging also allows doctors to group patients who have a similar prognosis (outlook), and it is not the same for all types of head and neck cancer. By grouping patients this way, doctors are able to more accurately predict outcomes for patients depending on the type of treatment they receive. In certain cancers, the stage is also determined by other factors. For throat cancer, the presence of human papillomavirus (HPV) and the location of the cancer cells are considered. For thyroid cancer, the subtype of cancer and age of the patient influence the stage. This information helps your doctor determine the best treatment options for you.

If your cancer returns after treatment, your doctor may repeat the diagnostic tests used originally to reassess your stage. This is known as restaging. If a new stage is assigned, it is often preceded by an "r" to denote that it has been restaged and is different from the original stage given at diagnosis.

Staging tables for each type of head and neck cancer start on page 2. Look carefully at the table headlines and sections to ensure you read the information that applies to your diagnosis because each has unique staging characteristics. ■

Testing for biomarkers

➡ ***Biomarkers are substances, such as genes and molecules, that are produced by cancer cells or other cells of the body in response to cancer. They can be measured in the blood, plasma, urine, cerebrospinal fluid or other body fluids or tissues. They are also known as tumor markers or biological markers. Testing for biomarkers is also known as molecular testing.***

Some biomarkers have been found that are associated with certain head and neck cancers. Testing for these biomarkers helps your doctor better diagnose and treat the cancer. With head and neck cancers, biomarkers are most often tested during staging, and the results help determine treatment.

Some of the biomarkers that may be tested if you have a head and neck cancer include the following.

Epstein-Barr virus (EBV) is associated with some nasopharyngeal cancers and may be tested to help make a diagnosis as well as assess the response of therapy and monitor for recurrence.

Human papillomavirus (HPV) is primarily tested with throat cancers as a part of the staging process. It has strains that are linked to throat cancer, specifically oropharyngeal (see *HPV and Cancer*, page 7). Research is still determining whether HPV is a biomarker for any of the other types of head and neck cancer.

Genes may be tested to determine a patient's eligibility to receive certain types of targeted therapy. Currently, therapies are approved for people with abnormalities in the *BRAF, RET, p53* and *NTRK* genes.

Programmed cell death-ligand 1 (PD-L1) helps determine whether a patient will respond to immunotherapy. At this time, it is the only biomarker to test for a response to immunotherapy in head and neck cancer.

Proteins and growth factors affect how tumor cells develop and survive. They are tested to determine whether a person has abnormalities in the vascular endothelial growth factor *(VEGF)*, epidermal growth factor receptor *(EGFR)* and the *MEK* protein. Some types of targeted therapy known as tyrosine kinase inhibitors (TKIs) are available to treat these abnormalities.

Thyroid hormone levels, such as thyroglobulin, thyroid-stimulating hormone and medullary type-specific tests, which include calcitonin and carcinoembryonic antigen levels, are biomarkers for thyroid cancer.

Research in clinical trials is ongoing to identify more biomarkers.

STAGES OF ORAL CANCER

CLASSIFYING ORAL CANCER

Classification	Definition
TUMOR (T)	
TX	Primary tumor cannot be assessed.
Tis	Carcinoma in situ.
T1	Tumor not more than 2 cm, with depth of invasion (DOI) not more than 5 mm. DOI is depth of invasion and not tumor thickness.
T2	Tumor not more than 2 cm, with DOI more than 5 mm *or* tumor more than 2 cm and not more than 4 cm, with DOI not more than 10 mm. DOI is depth of invasion and not tumor thickness.
T3	Tumor more than 2 cm and not more than 4 cm with DOI more than 10 mm; *or* tumor more than 4 cm with DOI not more than 10 mm. DOI is depth of invasion and not tumor thickness.
T4	Moderately advanced or very advanced local disease.
T4a	Moderately advanced local disease. Tumor more than 4 cm with DOI more than 10 mm *or* tumor invades adjacent structures only (e.g. through cortical bone of the mandible [lower jawbone] or maxilla [upper jawbone], or involves the maxillary sinus or skin of the face). DOI is depth of invasion and not tumor thickness.
T4b	Very advanced local disease. Tumor invades masticator space (located on either side of the face around the jawbones), pterygoid plates, or skull base and/or encases the internal carotid artery.
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(-).
N2	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(+); *or* larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-); *or* metastases in multiple ipsilateral lymph nodes, none larger than 6 cm in greatest dimension and ENE(-); *or* in bilateral (on both sides) or contralateral (on the opposite side) lymph node(s), none larger than 6 cm in greatest dimension, ENE(-).
N2a	Metastases in single ipsilateral (on the same side) node 3 cm or smaller in greatest dimension and ENE*(+); *or* a single ipsilateral node larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-).
N2b	Metastases in multiple ipsilateral (on the same side) nodes, none larger than 6 cm in greatest dimension and ENE*(-).
N2c	Metastases in bilateral (on both sides) or contralateral (on the opposite side) lymph node(s), none larger than 6 cm in greatest dimension and ENE*(-).
N3	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-); *or* metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
N3a	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-).
N3b	Metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE*(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

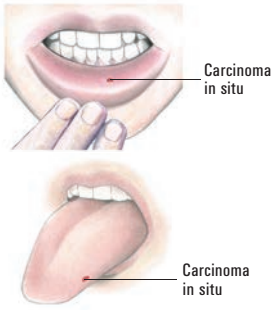
*Extranodal extension (ENE) refers to cancer cells that have spread beyond the lymph node into surrounding tissues.

STAGING ORAL CANCER

Stage	T	N	M
0	Tis	N0	M0
I	T1	N0	M0
II	T2	N0	M0
III	T3 T1, T2, T3	N0 N1	M0 M0
IVA	T4a T1, T2, T3, T4a	N0, N1 N2	M0 M0
IVB	Any T T4b	N3 Any N	M0 M0
IVC	Any T	Any N	M1

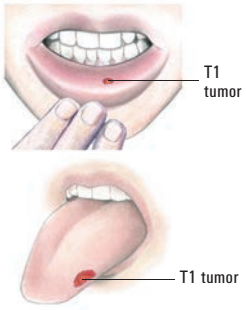
ILLUSTRATED STAGES OF ORAL CANCER

Stage 0



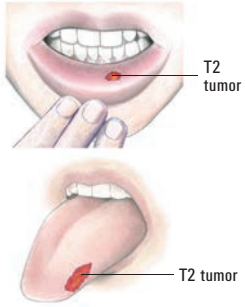
A cluster of malignant cells, known as carcinoma in situ, is present but has not spread to surrounding tissues.

Stage I



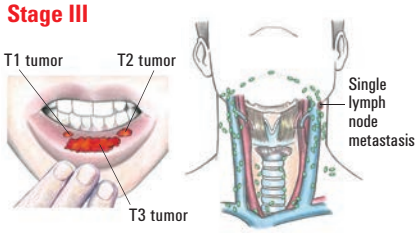
The tumor is not more than 2 cm with a depth of invasion (how deeply the tumor cells have invaded) of not more than 5 mm.

Stage II



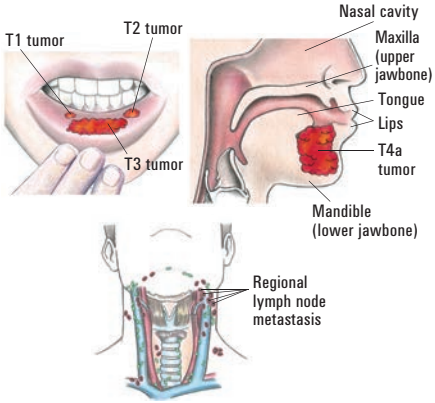
The tumor is not more than 2 cm with a depth of invasion (DOI) (how deeply the tumor cells have invaded) of more than 5 mm but not more than 10 mm, or the tumor is more than 2 cm but not more than 4 cm with a DOI of not more than 10 mm.

Stage III



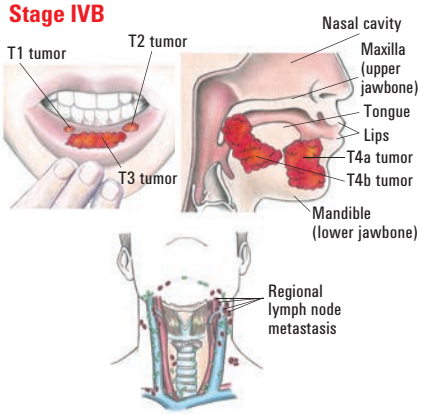
The tumor is not more than 2 cm with a depth of invasion (DOI) (how deeply the tumor cells have invaded) of not more than 5 mm (T1), or not more than 2 cm with a DOI of more than 5 mm but not more than 10 mm, or the tumor is more than 2 cm but not more than 4 cm with a DOI of not more than 10 mm (T2) and has spread to a single lymph node on the same side. Or, the tumor is more than 4 cm or any size with a DOI of more than 10 mm (T3) and may have spread to a single lymph node on the same side.

Stage IVA



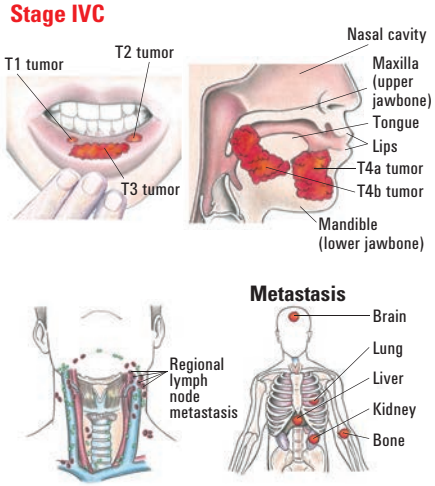
The tumor cells have invaded adjacent structures only, such as the lower or upper jawbone, sinus or skin of face, or extensive tumor with bilateral tongue involvement and/or depth of invasion (DOI) (how deeply the tumor cells have invaded) of more than 20 mm (T4a), and may have spread to one lymph node on the same side. Or, the tumor is 2 cm or smaller with a depth of invasion DOI of 5 mm or less (T1), 2 cm or less with a DOI of more than 5 mm but not more than 10 mm, or more than 2 cm but not more than 4 cm with a DOI of 10 mm or less (T2), or more than 4 cm or any size with a DOI of more than 10 mm (T3), or is a T4a tumor, and has spread to one or more lymph nodes.

Stage IVB



The tumor may be any size and has spread to one or more lymph nodes on one or both sides; or the tumor cells have spread to the jawbones, skull bone and/or encases the carotid artery (T4b) and may have spread to one or more lymph nodes.

Stage IVC



The tumor can be any size, may have spread to one or more lymph nodes and has spread to distant parts of the body.

SCAN TO ALSO VIEW STAGING ILLUSTRATIONS ONLINE FOR ORAL CANCER

All of the staging tables on pages 2 through 5 are used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.

STAGES OF MAJOR SALIVARY GLAND CANCER

CLASSIFYING MAJOR SALIVARY GLAND CANCER

Classification / Definition	
TUMOR (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
Tis	Carcinoma in situ.
T1	Tumor 2 cm or smaller in greatest dimension without extraparenchymal extension (spread to surrounding tissues).
T2	Tumor larger than 2 cm but not larger than 4 cm in greatest dimension without extraparenchymal extension (spread to surrounding tissues).
T3	Tumor larger than 4 cm and/or tumor having extraparenchymal extension (spread to surrounding tissues).
T4	Moderately advanced or very advanced disease.
T4a	Moderately advanced disease. Tumor invades skin, mandible (lower jaw), ear canal, and/or facial nerve.
T4b	Very advanced local disease. Tumor invades skull base and/or pterygoid plates and/or encases carotid artery.
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(-).
N2	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(+); *or* larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-); *or* metastases in multiple ipsilateral lymph nodes, none larger than 6 cm in greatest dimension and ENE(-); *or* in bilateral (on both sides) or contralateral (on the opposite side) lymph node(s), none larger than 6 cm in greatest dimension, ENE(-).
N2a	Metastasis in single ipsilateral (on the same side) node 3 cm or smaller in greatest dimension and ENE*(+); *or* a single ipsilateral node larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-).
N2b	Metastases in multiple ipsilateral (on the same side) nodes none larger than 6 cm in greatest dimension and ENE*(-).
N2c	Metastases in bilateral (on both sides) or contralateral (on the opposite side) lymph nodes, none larger than 6 cm in greatest dimension and ENE*(-).
N3	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-); *or* metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
N3a	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE(-).
N3b	Metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE*(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

*Extranodal extension (ENE) refers to cancer cells that have spread beyond the lymph node into surrounding tissues.

STAGING MAJOR SALIVARY GLAND CANCER

Stage	T	N	M
0	Tis	N0	M0
I	T1	N0	M0
II	T2	N0	M0
III	T3 T0, T1, T2, T3	N0 N1	M0 M0
IVA	T4a T0, T1, T2, T3, T4a	N0, N1 N2	M0 M0
IVB	Any T T4b	N3 Any N	M0 M0
IVC	Any T	Any N	M1

SCAN TO VIEW STAGING ILLUSTRATIONS FOR MAJOR SALIVARY GLAND CANCER

STAGES OF SINUS & NASAL CANCER

CLASSIFYING SINUS & NASAL CANCER

Classification / Definition	
TUMOR (T)	
TX	Primary tumor cannot be assessed.
Tis	Carcinoma in situ.
Maxillary Sinus	
T1	Tumor limited to maxillary sinus mucosa with no erosion or destruction of bone.
T2	Tumor causing bone erosion or destruction including extension into the hard palate and/or middle nasal meatus, except extension to posterior wall of maxillary sinus and pterygoid plates.
T3	Tumor invades any of the following: bone of the posterior wall of maxillary sinus, subcutaneous tissues, floor or medial wall of orbit (eye socket), pterygoid fossa, ethmoid sinuses.
T4	Moderately advanced or very advanced local disease.
T4a	Moderately advanced local disease. Tumor invades anterior orbital contents (eye socket), skin of cheek, pterygoid plates, infratemporal fossa, cribriform plate, sphenoid or frontal sinuses.
T4b	Very advanced local disease. Tumor invades any of the following: orbital apex (eye socket), dura (membrane surrounding the brain and spinal cord), brain, middle cranial fossa, cranial nerves other than maxillary division of trigeminal nerve (V2), nasopharynx (upper part of throat) or clivus (bony base of skull).
Nasal Cavity and Ethmoid Sinus	
T1	Tumor restricted to any one subsite, with or without bony invasion.
T2	Tumor invading two subsites in a single region or extending to involve an adjacent region within the nasoethmoidal complex, with or without bony invasion.
T3	Tumor extends to invade the medial wall or floor of the orbit (eye socket), maxillary sinus, palate, or cribriform plate.
T4	Moderately advanced or very advanced local disease.
T4a	Moderately advanced local disease. Tumor invades any of the following: anterior orbital contents (eye socket), skin of nose or cheek, minimal extension to anterior cranial fossa, pterygoid plates, sphenoid or frontal sinuses.
T4b	Very advanced local disease. Tumor invades any of the following: orbital apex (eye socket), dura (membrane surrounding the brain and spinal cord), brain, middle cranial fossa, cranial nerves other than (V2), nasopharynx (upper part of throat) or clivus (bony base of skull).
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(-).
N2	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(+); *or* larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-); *or* metastases in multiple ipsilateral lymph nodes, none larger than 6 cm in greatest dimension and ENE(-); *or* in bilateral (on both sides) or contralateral (on the opposite side) lymph node(s), none larger than 6 cm in greatest dimension and ENE(-).
N2a	Metastasis in single ipsilateral (on the same side) node 3 cm or smaller in greatest dimension and ENE*(+); *or* a single ipsilateral node larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-).
N2b	Metastases in multiple ipsilateral (on the same side) nodes none larger than 6 cm in greatest dimension and ENE*(-).
N2c	Metastases in bilateral (on both sides) or contralateral (on the opposite side) lymph node(s), none larger than 6 cm in greatest dimension and ENE*(-).
N3	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-); *or* metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
N3a	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-).
N3b	Metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE*(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

*Extranodal extension (ENE) refers to cancer cells that have spread beyond the lymph node into surrounding tissues.

STAGING SINUS & NASAL CANCER

Stage	T	N	M
0	Tis	N0	M0
I	T1	N0	M0
II	T2	N0	M0
III	T3 T1, T2, T3	N0 N1	M0 M0
IVA	T4a T1, T2, T3, T4a	N0, N1 N2	M0 M0
IVB	Any T T4b	N3 Any N	M0 M0
IVC	Any T	Any N	M1

SCAN TO VIEW STAGING ILLUSTRATIONS FOR SINUS & NASAL CANCER

STAGES OF THROAT CANCER (OROPHARYNGEAL, HYPOPHARYNGEAL, NASOPHARYNGEAL)

(HPV-) CLASSIFYING OROPHARYNGEAL AND HYPOPHARYNGEAL CANCERS

Classification / Definition	
TUMOR (T)	
TX	Primary tumor cannot be assessed.
Tis	Carcinoma in situ.
Oropharyngeal (HPV-)	
T1	Tumor 2 cm or smaller in greatest dimension.
T2	Tumor larger than 2 cm but not larger than 4 cm in greatest dimension.
T3	Tumor larger than 4 cm in greatest dimension or extension to lingual surface of epiglottis.
T4	Moderately advanced or very advanced local disease.
T4a	Moderately advanced local disease. Tumor invades the larynx, extrinsic muscle of tongue, medial pterygoid, hard palate or mandible (jawbone).
T4b	Very advanced local disease. Tumor invades lateral pterygoid muscle, pterygoid plates, lateral nasopharynx, or skull base or encases carotid artery.
Hypopharyngeal	
T1	Tumor limited to one subsite of hypopharynx and/or 2 cm or smaller in greatest dimension.
T2	Tumor invades more than one subsite of hypopharynx or an adjacent site, or measures larger than 2 cm but not larger than 4 cm in greatest dimension without fixation of hemilarynx.
T3	Tumor larger than 4 cm in greatest dimension or with fixation of hemilarynx or extension to esophageal mucosa.
T4	Moderately advanced and very advanced local disease.
T4a	Moderately advanced local disease. Tumor invades thyroid/cricoid cartilage, hyoid bone, thyroid gland, esophageal muscle or central compartment soft tissue.
T4b	Very advanced local disease. Tumor invades prevertebral fascia, encases carotid artery or involves mediastinal structures.
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(-).
N2	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(+); *or* larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-); *or* metastases in multiple ipsilateral lymph nodes, none larger than 6 cm in greatest dimension and ENE(-); *or* in bilateral (on both sides) or contralateral (on the opposite side) lymph node(s), none larger than 6 cm in greatest dimension and ENE(-).
N2a	Metastasis in a single ipsilateral (on the same side) node 3 cm or smaller in greatest dimension and ENE*(+); *or* a single ipsilateral node larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-).
N2b	Metastases in multiple ipsilateral (on the same side) nodes none larger than 6 cm in greatest dimension and ENE*(-).
N2c	Metastases in bilateral (on both sides) or contralateral (on the opposite side) lymph nodes, none larger than 6 cm in greatest dimension and ENE*(-).
N3	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-); *or* metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
N3a	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-).
N3b	Metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE*(+); *or* multiple ipsilateral, contralateral (on the opposite side) or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

*Extranodal extension (ENE) refers to cancer cells that have spread beyond the lymph node into surrounding tissues.

(HPV-) STAGING OROPHARYNGEAL AND HYPOPHARYNGEAL CANCERS

Stage	T	N	M
0	Tis	N0	M0
I	T1	N0	M0
II	T2	N0	M0
III	T3 T1, T2, T3	N0 N1	M0 M0
IVA	T4a T1, T2, T3, T4a	N0, N1 N2	M0 M0
IVB	Any T T4b	N3 Any N	M0 M0
IVC	Any T	Any N	M1

SCAN TO VIEW STAGING ILLUSTRATIONS FOR THROAT CANCER

(HPV+) CLASSIFYING OROPHARYNGEAL CANCER

Classification / Definition	
TUMOR (T)	
T0	No primary identified.
T1	Tumor 2 cm or smaller in greatest dimension.
T2	Tumor larger than 2 cm but not larger than 4 cm in greatest dimension.
T3	Tumor larger than 4 cm in greatest dimension or extension to lingual surface of epiglottis.
T4	Moderately advanced local disease. Tumor invades the larynx, extrinsic muscle of tongue, medial pterygoid, hard palate or mandible (jawbone) or beyond.
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Metastasis in four or fewer lymph nodes.
N2	Metastasis in more than four lymph nodes.
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

(HPV+) STAGING OROPHARYNGEAL CANCER

Stage	T	N	M
I	T0, T1, T2	N0, N1	M0
II	T0, T1, T2 T3, T4	N2 N0, N1	M0 M0
III	T3, T4	N2	M0
IV	Any T	Any N	M1

CLASSIFYING NASOPHARYNGEAL CANCER

Classification / Definition	
TUMOR (T)	
TX	Primary tumor cannot be assessed.
T0	No tumor identified, but EBV*-positive cervical node(s) involvement.
Tis	Carcinoma in situ.
T1	Tumor confined to nasopharynx (behind nasal cavity/upper part of throat), or extension to oropharynx and/or nasal cavity without parapharyngeal involvement.
T2	Tumor with extension to parapharyngeal space, and/or adjacent soft tissue involvement (medial pterygoid, lateral pterygoid, prevertebral muscles).
T3	Tumor with infiltration of bony structures at skull base, cervical vertebra, pterygoid structures, and/or paranasal sinuses.
T4	Tumor with intracranial extension, involvement of cranial nerves, hypopharynx, orbit, parotid gland, and/or extensive soft tissue infiltration beyond the lateral surface of the lateral pterygoid muscle.
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Unilateral (on one side) metastasis in cervical lymph node(s) and/or unilateral or bilateral metastasis (on both sides) in retropharyngeal lymph node(s), 6 cm or smaller in greatest dimension, above the caudal border of cricoid cartilage.
N2	Bilateral metastasis in cervical lymph node(s), 6 cm or smaller in greatest dimension, above the caudal border of cricoid cartilage.
N3	Unilateral (on one side) or bilateral (on both sides) metastasis in cervical lymph node(s), larger than 6 cm in greatest dimension, and/or extension below the caudal border of cricoid cartilage.
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

*Epstein-Barr virus

STAGING NASOPHARYNGEAL CANCER

Stage	T	N	M
0	Tis	N0	M0
I	T1	N0	M0
II	T0, T1, T2 T2	N1 N0	M0 M0
III	T0, T1, T2, T3 T3 T3	N2 N0 N1	M0 M0 M0
IVA	T4 T4 T4 Any T	N0 N1 N2 N3	M0 M0 M0 M0
IVB	Any T	Any N	M1

STAGES OF THYROID CANCER

CLASSIFYING THYROID CANCER

Classification / Definition	
TUMOR (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
Anaplastic & Differentiated	
T1	Tumor ≤ (not more than) 2 cm in greatest dimension limited to the thyroid.
T1a	Tumor ≤ (not more than) 1 cm in greatest dimension limited to the thyroid.
T1b	Tumor > (more than) 1 cm but ≤ (not more than) 2 cm in greatest dimension limited to the thyroid.
T2	Tumor > (more than) 2 cm but ≤ (not more than) 4 cm in greatest dimension limited to the thyroid.
T3	Tumor > (more than) 4 cm limited to the thyroid, or gross extrathyroidal extension (extended beyond the thyroid) invading only strap muscles.
T3a	Tumor > (more than) 4 cm limited to the thyroid.
T3b	Gross extrathyroidal extension (extended beyond the thyroid) invading only strap muscles (sternohyoid, sternothyroid, thyrohyoid or omohyoid muscles) from a tumor of any size.
T4	Includes gross extrathyroidal extension (extended beyond the thyroid) beyond the strap muscles.
T4a	Gross extrathyroidal extension (extended beyond the thyroid) invading subcutaneous soft tissues, larynx, trachea, esophagus, or recurrent laryngeal nerve from a tumor of any size.
T4b	Gross extrathyroidal extension (extended beyond the thyroid) invading prevertebral fascia or encasing the carotid artery or mediastinal vessels from a tumor of any size.
Medullary	
T1	Tumor is ≤ (not more than) 2 cm in greatest dimension limited to the thyroid.
T1a	Tumor is ≤ (not more than) 1 cm in greatest dimension limited to the thyroid.
T1b	Tumor is > (more than) 1 cm but ≤ (not more than) 2 cm in greatest dimension limited to the thyroid.
T2	Tumor is > (more than) 2 cm but ≤ (not more than) 4 cm in greatest dimension limited to the thyroid.
T3	Tumor is > (more than) 4 cm or with extrathyroidal extension (extended beyond the thyroid).
T3a	Tumor is > (more than) 4 cm in greatest dimension limited to the thyroid.
T3b	Tumor of any size with gross extrathyroidal extension (extended beyond the thyroid) invading only strap muscles (sternohyoid, sternothyroid, thyrohyoid or omohyoid muscles).
T4	Advanced disease.
T4a	Moderately advanced disease; tumor of any size with gross extrathyroidal extension (extended beyond the thyroid) into the nearby tissues of the neck, including subcutaneous soft tissue, larynx, trachea, esophagus or recurrent laryngeal nerve.
T4b	Very advanced disease; tumor of any size with extension toward the spine or into nearby large blood vessels, gross extrathyroidal extension (extended beyond the thyroid) invading the prevertebral fascia, or encasing the carotid artery or mediastinal vessels.
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No evidence of locoregional lymph node metastasis.
N0a	One or more cytologically (based on fine needle aspiration biopsy) or histologically (based on pathologic analysis of tissues after surgery) confirmed benign lymph nodes.
N0b	No radiologic or clinical evidence of locoregional lymph node metastasis.
N1	Metastasis to regional nodes.
N1a	Metastasis to level VI or VII (pretracheal, paratracheal, or prelaryngeal/Delphian, or upper mediastinal) lymph nodes. This can be unilateral (on one side) or bilateral (on both sides) disease.
N1b	Metastasis to unilateral (on one side), bilateral (on both sides), or contralateral (opposite side of thyroid tumor) lateral lymph nodes (levels I, II, III, IV or V) or retropharyngeal lymph nodes.
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

STAGING MEDULLARY THYROID CANCER

Stage	T	N	M
I	T1	N0	M0
II	T2, T3	N0	M0
III	T1 - T3	N1a	M0
IVA	T4a T1 - T3	Any N N1b	M0 M0
IVB	T4b	Any N	M0
IVC	Any T	Any N	M1

STAGING DIFFERENTIATED THYROID CANCER*

Stage	T	N	M
Younger than 55 years			
I	Any T	Any N	M0
II	Any T	Any N	M1
55 years or older			
I	T1, T2	N0/NX	M0
II	T1, T2 T3a, T3b	N1 Any N	M0 M0
III	T4a	Any N	M0
IVA	T4b	Any N	M0
IVB	Any T	Any N	M1

*Includes papillary, follicular, poorly differentiated and Hurthle cell carcinoma

STAGING ANAPLASTIC THYROID CANCER

Stage	T	N	M
IVA	T1 - T3a	N0/NX	M0
IVB	T1 - T3a T3b, T4	N1 Any N	M0 M0
IVC	Any T	Any N	M1

SCAN TO VIEW STAGING ILLUSTRATIONS FOR THYROID CANCER

STAGING LARYNGEAL CANCER

Stage	T	N	M
0	Tis	N0	M0
I	T1	N0	M0
II	T2	N0	M0
III	T3 T1, T2, T3	N0 N1	M0 M0
IVA	T4a T1, T2, T3, T4a	N0, N1 N2	M0 M0
IVB	Any T T4b	N3 Any N	M0 M0
IVC	Any T	Any N	M1

STAGES OF LARYNGEAL CANCER

CLASSIFYING LARYNGEAL CANCER

Classification / Definition	
TUMOR (T)	
TX	Primary tumor cannot be assessed.
Tis	Carcinoma in situ.
Supraglottis	
T1	Tumor limited to one subsite of supraglottis with normal vocal cord mobility.
T2	Tumor invades mucosa of more than one adjacent subsite of supraglottis or glottis or region outside the supraglottis (e.g., mucosa of base of tongue, vallecula, medial wall of pyriform sinus) without fixation of the larynx.
T3	Tumor limited to larynx with vocal cord fixation and/or invades any of the following: postcricoid area, preepiglottic space, paraglottic space, and/or inner cortex of thyroid cartilage.
T4	Moderately advanced or very advanced.
T4a	Moderately advanced local disease. Tumor invades through the outer cortex of the thyroid cartilage and/or invades tissues beyond the larynx (e.g., trachea, soft tissues of neck including deep extrinsic muscle of the tongue, strap muscles, thyroid or esophagus).
T4b	Very advanced local disease. Tumor invades prevertebral space, encases carotid artery, or invades mediastinal structures.
Glottis	
T1	Tumor limited to the vocal cord(s) (may involve anterior or posterior commissure) with normal mobility.
T1a	Tumor limited to one vocal cord.
T1b	Tumor involves both vocal cords.
T2	Tumor extends to supraglottis and/or subglottis, and/or with impaired vocal cord mobility.
T3	Tumor limited to the larynx with vocal cord fixation and/or invasion of paraglottic space and/or inner cortex of the thyroid cartilage.
T4	Moderately advanced or very advanced.
T4a	Moderately advanced local disease. Tumor invades through the outer cortex of the thyroid cartilage and/or invades tissues beyond the larynx (e.g., trachea, cricoid cartilage, soft tissues of neck including deep extrinsic muscle of the tongue, strap muscles, thyroid or esophagus).
T4b	Very advanced local disease. Tumor invades prevertebral space, encases carotid artery or invades mediastinal structures.
Subglottis	
T1	Tumor limited to the subglottis.
T2	Tumor extends to vocal cord(s) with normal or impaired mobility.
T3	Tumor limited to larynx with vocal cord fixation and/or invasion of paraglottic space and/or inner cortex of the thyroid cartilage.
T4	Moderately advanced or very advanced.
T4a	Moderately advanced local disease. Tumor invades cricoid or thyroid cartilage and/or invades tissues beyond the larynx (e.g., trachea, soft tissues of neck including deep extrinsic muscles of the tongue, strap muscles, thyroid, or esophagus).
T4b	Very advanced local disease. Tumor invades prevertebral space, encases carotid artery or invades mediastinal structures.
NODE (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(-).
N2	Metastasis in a single ipsilateral (on the same side) lymph node 3 cm or smaller in greatest dimension and ENE*(+); *or* larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-); *or* metastases in multiple ipsilateral lymph nodes none larger than 6 cm in greatest dimension and ENE(-); *or* in bilateral (on both sides) or contralateral (on the opposite side) lymph node(s), none larger than 6 cm in greatest dimension and ENE(-).
N2a	Metastasis in single ipsilateral (on the same side) node 3 cm or smaller in greatest dimension and ENE*(+); *or* a single ipsilateral node, larger than 3 cm but not larger than 6 cm in greatest dimension and ENE(-).
N2b	Metastasis in multiple ipsilateral (on the same side) nodes none larger than 6 cm in greatest dimension and ENE*(-).
N2c	Metastases in bilateral (on both sides) or contralateral (on the opposite side) lymph nodes, none larger than 6 cm in greatest dimension and ENE*(-).
N3	Metastasis in a lymph node larger than 6 cm in greatest dimension and ENE*(-); *or* metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE(+); *or* multiple ipsilateral, contralateral (on the opposite side), or bilateral (on both sides) lymph nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
N3a	Metastasis in a lymph node, larger than 6 cm in greatest dimension and ENE*(-).
N3b	Metastasis in a single ipsilateral (on the same side) node larger than 3 cm in greatest dimension and ENE*(+); *or* multiple ipsilateral, contralateral (on the opposite side), or bilateral (on both sides) nodes, any with ENE(+); *or* a single contralateral node of any size and ENE(+).
METASTASIS (M)	
M0	No distant metastasis.
M1	Distant metastasis.

*Extranodal extension (ENE) refers to cancer cells that have spread beyond the lymph node into surrounding tissues.

SCAN TO VIEW STAGING ILLUSTRATIONS FOR LARYNGEAL CANCER

Improved therapies offer more options and better outcomes

Advances in understanding and treating head and neck cancer are bringing hope to many people affected by this disease. More treatments are now available, and research in clinical trials is ongoing to find more effective therapies and better ways to manage side effects of the disease and its treatment.

After you receive a diagnosis, you will work closely with your doctor to develop a treatment plan. It is an important time to discuss your concerns and your expectations for maintaining independence with certain physical activities of daily living, as treatment may change the way you breathe, speak or eat. Your doctor will focus on preserving – as much as possible – your ability to perform these functions normally.

Try to learn as much as you can before you begin treatment so you are not surprised later. It is crucial that you are comfortable with your decision. Always request explanations for anything you do not understand.

Your doctor may ask you about your smoking status to determine the potential effectiveness of radiation therapy and surgical treatments. Smoking is known to reduce treatment effectiveness and is also associated with an increased risk of second cancers.

Throughout treatment, your doctor will continually monitor your condition and make adjustments as needed. Keep in mind that cancer is an ever-changing condition that presents many challenges.

TREATMENT OPTIONS

Treatments are described as first line, second line and so on. First-line therapy is the first treatment used. Second-line therapy is given when the first-line therapy doesn't work or is no longer effective. You may also hear a treatment called standard of care, which refers to the best treatment known for a specific type and stage of cancer.

Following are some of the common treatments for head and neck cancers. For more specific options, go to *Treatment by Cancer Type*, page 10.

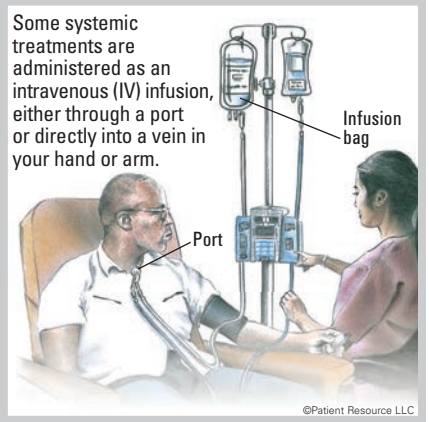
Surgery is used to remove a solid tumor. It may offer the best chance of controlling the disease and keeping it from spreading, especially for people with early-stage disease. Surgery may be used to stage and treat the cancer or to relieve or prevent symptoms that might otherwise occur later. Many types of surgery are available. A neck dissection, which is the removal of lymph nodes and surrounding tissue from the neck, is a common procedure that may be used. Surgery may also accompany other treatment types.

Reconstructive surgery may be an option to restore appearance or functionality (see *Reconstruction & Rehabilitation*, page 19).

Radiation therapy uses high-energy radiation to destroy cancer cells and shrink tumors. Some people with localized disease or bone pain that does not lessen with chemotherapy may receive it to specific parts of the body.

External-beam radiation therapy (EBRT) is delivered from a machine and is used to treat many types of head and neck cancer. Different types of EBRT include proton therapy, three-dimensional conformal radiation therapy (3D-CRT), intensity-modulated radiation therapy (IMRT), hyperfractionated therapy and stereotactic radiosurgery.

FIGURE 1
DRUG THERAPY



Internal radiation therapy, also called brachytherapy, uses a radioactive substance sealed in needles, seeds, wires or catheters that are placed directly into or near the cancer.

Radioactive iodine treatment involves giving radioactive iodine (I-131) in liquid or pill form to treat some forms of thyroid cancer. It may be used after surgery in patients with thyroid cancer who are at increased risk of recurrence. The radioactive iodine will concentrate in any remaining thyroid tissue, and the radiation will kill the cancer cells.

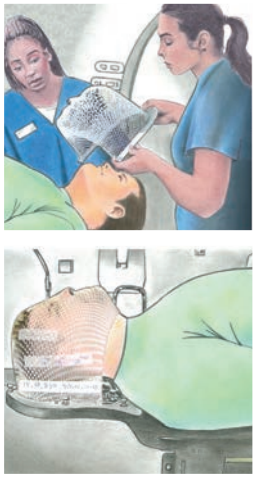
Drug therapy is systemic therapy that travels throughout the body and may include chemotherapy, hormone therapy, immunotherapy or targeted therapy (see Figure 1).

THERMOPLASTIC MASK

A necessary safety measure during radiation therapy

For radiation therapy to be most effective, the radiation beams must target the same spot every time. In most cases, semi-permanent marks or permanent tattoos are placed on your skin to indicate the exact location the radiation beams must hit to reach the tumor. To ensure your safety, you must be in the same position for every treatment.

Body molds or other immobilizing devices, such as a special mesh head mask called a thermoplastic mask, may be necessary. The mask is created from a mold of your face and head and is a tight fit. Wearing it and being unable to move can cause anxiety, especially if you are claustrophobic. Your treatment team will help make you as comfortable as possible, so tell them if you feel anxious. Your doctor may prescribe medication to help you relax.



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Chemotherapy is typically part of the treatment plan for most types of head and neck cancer. It may be given alone or in combination with other forms of treatment. In early stages, it may be used before surgery (neoadjuvant) to help shrink the tumor, or after surgery (adjuvant) to kill remaining cells. It may be given intravenously (IV) through a small tube inserted into a vein or port, or taken orally as a pill. It is typically delivered in cycles, with treatment periods followed by rest periods to give the body time to recover.

Hormone therapy is a part of treatment, if the thyroid is partially or fully removed, to supplement the hormone the gland makes. It may also be used to slow down the growth of remaining differentiated cancer cells. It is typically given as a pill that is taken daily.

Immunotherapy helps the body's own immune system recognize and destroy cancer cells. It may be used as first-line therapy for metastatic, recurrent or unresectable (inoperable) head and neck cancers. And, it may be indicated when the cancer progresses on or after platinum-based chemotherapy. By training the immune system to respond to cancer, this strategy has the potential for a response that can extend beyond the end of treatment. The main type of immunotherapy approved for head and neck cancers is immune checkpoint inhibitors, which prevent the immune response from slowing down, so that immune cells continue fighting cancer. It may be given intravenously (IV) through a vein or a port or as an injection.

Targeted therapy uses drugs or other substances to identify and attack specific types of cancer cells. Targeted therapy is designed to affect only cancer cells. Some of these drugs are oral medications given in pill form, and others are given by IV. Some may be given alone or in combination with other drug therapies.

When given for head and neck cancers, these drugs target specific genes, such as *BRAF, RET* and *NTRK,* or proteins and growth factors, including *VEGF, EGFR* and *MEK*. It may be used with or without chemotherapy and after surgery for advanced stage head and neck cancers.

Chemoradiation, also called chemoradiotherapy, combines chemotherapy with radiation therapy. It makes cancer cells more sensitive to radiation, making it easier for the radiation to kill them.

Watchful waiting, sometimes known as active surveillance, may be recommended for tumors that appear to be growing very slowly. Delaying treatment postpones potential treatment side effects for as long as possible while the doctor closely monitors for signs the cancer has progressed or returned.

Clinical trials are medical research studies that may offer access to leading-edge treatments not yet widely available. They may be an option at any stage, even as a first-line treatment (see *Clinical Trials,* page 8). Ask your doctor if you should consider a clinical trial. ■

HPV and Cancer

Human papillomavirus (HPV), a virus that can lead to cancer, is the most common sexually transmitted disease in the United States. Most people acquire it at some point in their lifetime, and the majority are able to heal from the infection, often without symptoms. If the infection does not resolve, however, it may lead to the development of cancer.

Key facts about HPV:

- More than 150 types of HPV exist and about 40 types can be spread through sexual contact from the skin and mucous membranes (lining of the mouth, throat or genital tract).
- HPV-related throat cancers are increasing fastest among men in the United States.
- Nine strains of HPV are known to cause cancer, with HPV being linked to approximately 70 percent of oropharyngeal (throat) cancers.
- Oropharyngeal cancers affect the middle part of the throat, including the base of the tongue and tonsils, and are the most common type of cancer caused by HPV.
- HPV is also linked to anal, cervical, penile, vaginal and vulvar cancers.

If your doctor suspects throat cancer, you will likely be tested for the HPV biomarker. Its presence helps your doctor appropriately stage the cancer and determine the treatment that may be most effective for you (see *Throat Cancer*, page 11). HPV biomarker testing may also be conducted to predict an HPV-associated throat cancer recurrence.

Your health care team and the listings in the back of this guide are valuable resources for learning more about HPV and how your diagnosis may affect your loved ones. Ask your doctor about the recommended screenings and vaccinations for your partner and your children, as well as the potential benefit of being vaccinated after receiving your head and neck cancer diagnosis. Although HPV vaccination does not treat existing infections or diseases (this is why the HPV vaccine works best when given before any exposure to HPV), it can prevent new infections with the types of HPV that most often cause oropharyngeal and other cancers.

Three vaccines are approved by the U.S. Food and Drug Administration (FDA) for male and female children and young adults, 9 to 26 years old, to provide protection against new HPV infections and include:

- **Gardasil** (Human Papillomavirus Quadrivalent [Types 6, 11, 16, and 18] Vaccine, Recombinant).
- **Gardasil 9** (Human Papillomavirus 9-valent Vaccine, Recombinant). Gardasil 9's approval was recently expanded to include males and females ages 27 through 45 years.
- **Cervarix** (Human Papillomavirus Bivalent [Types 16 and 18] Vaccine, Recombinant).

Making certain lifestyle choices may help decrease the chance of getting the virus, such as using condoms and dental dams properly to lower the chance that HPV is passed from one person to another.

SOME HEAD AND NECK CANCER DRUGS

These therapies may be used alone or in combination. For additional combination therapies your doctor might suggest, go to PatientResource.com/Head_and_Neck_Treatment.aspx

- bleomycin sulfate (Blenoxane)
- cabozantinib (Cabometyx, Cometriq)
- cetuximab (Erbitux)
- cisplatin (Platinol)
- dabrafenib (Tafinlar) and trametinib (Mekinist)
- docetaxel (Taxotere)
- doxorubicin hydrochloride (Adriamycin)
- entrectinib (Rozlytrek)
- hydroxyurea (Hydrea)
- larotrectinib (Vitrakvi)
- lenvatinib (Lenvima)
- methotrexate sodium (Methotrexate LPF)
- nivolumab (Opdivo)
- pembrolizumab (Keytruda)
- pralsetinib (Gavreto)
- selpercatinib (Retevmo)
- sorafenib (Nexavar)
- vandetanib (Caprelsa)

As of 8/9/22

Research and invention lead to treatment advances

Clinical trials are studies that evaluate whether a new treatment, such as a drug, drug combination, surgical procedure, type of radiation therapy or a combination of therapies, is equally or more effective than the current standard of care. Some clinical trials may evaluate whether a new treatment that has fewer side effects may be as effective as the current standard of care.

Although it is often thought of as a last resort only, a clinical trial is a treatment option that can be considered from diagnosis through survivorship. In some cases, a clinical trial may even be your best first option.

A clinical trial is often introduced at diagnosis when you and your doctor are discussing your initial treatment plan, especially if your type of cancer has few or no approved therapies. A trial could also be incorporated into your treatment plan later if your cancer progresses, your current treatment is no longer effective or you are experiencing side effects that disrupt your quality of life. Sometimes, when cancer progresses, genomic testing may reveal a new mutation that may make you eligible for a clinical trial testing a therapy designed to treat that specific mutation.

Facing a life-changing decision is easier when you feel informed and safe. It is important to understand that most cancer treatments used today were once therapies or procedures that were developed, tested and evaluated through the clinical trials process to gain approval from the U.S. Food and Drug Administration (FDA). Understanding more about the process may help.

LEARN MORE TO MOVE FORWARD CONFIDENTLY

Generally, the studies happen in four phases. Each phase provides the building blocks of knowledge for the next phase. This approach allows researchers to ask and answer questions in a way that produces the most reliable information and provides the most protection to clinical trial participants. The process also ensures that only treatments that have been rigorously researched are approved for the public.

Based on the successes of other trials, the FDA recently has shortened its approval times for new therapies. Researchers have begun investigating and conducting seamless trials that begin in earlier phases. Today, the FDA considers approvals at any phase of research, including as early as Phase I trials, and approves therapies before many other countries' organizations. These advances give patients the earliest possible access to lifesaving treatments.

Phase I evaluates a new drug (or other type of treatment) to see if it is safe for use in people. The goal is to determine how and when the drug should be given, and the dosage that will be most effective for killing diseased cells while causing the fewest side effects.

Phase II determines how well a treatment works and how safe it is in a greater number of patients.

Phase III compares the new treatment with the current standard of care to see if it is more effective or has fewer side effects.

Phase IV tests a drug that has already been FDA-approved for the market to gather more information about its effect in different populations and learn about long-term side effects. ■

How you can search for a clinical trial

While your medical team works behind the scenes to identify a trial that may benefit you, you can take an active role in your care by joining in the search. Here's how to get started:

1. **Have your exact diagnosis, pathology report and details of previous treatments available.** That will help you narrow the list of trials that are currently underway to those that may be a good fit for you.
2. **Search online.** Many websites offer ways to search for a clinical trial. Some are customized to a certain cancer type; others are much broader. Generally, clinical trial search sites are hosted by the government, the National Cancer Institute, cancer advocacy groups, pharmaceutical companies and industry trade organizations, academic medical centers and major hospitals. No single list contains every open clinical trial, and new trials are continually being added, so check back often. For a list of clinical trials websites, see page 23.
3. **Request assistance by phone.** This is convenient for people who are not tech-savvy, do not have access to the tools necessary to search online or simply prefer to talk to a person.

As you search, look for trials that include your cancer type, age, location and the distance you are willing to travel. Once you find one or more trials you are interested in, talk with your doctor to determine whether you are eligible. Every participant in a specific trial must meet the same criteria to ensure the data gathered during the trial is valid.

Common criteria include cancer type, subtype, stage, biomarker status and treatment history. Keep in mind that you may not qualify for every trial that appeals to you. Some may be closed, or you may not meet eligibility criteria. For example, if a trial requires that you have already had a specific treatment and you have not, you will not be eligible.

Under certain extreme conditions, you and your doctor may apply to the U.S. Food and Drug Administration (FDA) to join a clinical trial that is closed or otherwise inaccessible. This is known as Expanded Access, also called Compassionate Use.

If you are interested in helping improve the future of cancer care but prefer not to participate in a therapeutic trial, consider a non-treatment trial that evaluates the following:

- Disease prevention and patient screening methods
- Diagnostic tools and procedures
- Genetic risk factors
- Ways to improve health and/or quality of life

Bill McCone was devastated after receiving a diagnosis of Stage IVA squamous cell carcinoma of the throat at 51. When his first treatment failed, his doctor offered the possibility of an immunotherapy clinical trial. He jumped at the chance and liked the opportunity of helping future head and neck cancer patients. Today, the cancer is undetectable, and he and his wife are traveling and enjoying life.

Survivor credits immunotherapy with saving his life

While shaving one morning, I found a lump on the left side of my neck that warranted a visit to my primary care doctor. After examining it, he was concerned enough to send me to an ENT. A CT scan showed the lump was an enlarged lymph node, and a biopsy determined it was squamous cell carcinoma but he was unsure of the origin.

Needing more information, I contacted a cancer hospital recommended by a friend who had been treated for breast cancer there. More testing discovered the cancer was in my left tonsil. A laparoscopic biopsy of my tonsil confirmed it was Stage IVA squamous cell carcinoma caused by HPV.

It felt like my whole world stopped while everyone else's lives were chugging along like normal. But, I felt confident in this cancer center, which was also a teaching hospital. Working with their oncologists gave me the hope I needed to keep going.

The oncologist there gave me several treatment options: platinum chemotherapy, surgery or targeted therapy plus radiation therapy. The side effects of chemotherapy frightened me. There was a risk of hearing loss, and a hearing test showed I already had high frequency hearing loss. Surgery could damage the nerves in my neck and could affect my ability to raise my left arm. So, I chose the option that combined targeted therapy with radiation therapy.

To begin, I received a port and started targeted therapy, was fitted for a fiberglass radiation mask and had three dots tattooed on my throat to pinpoint exactly where the radiation beams needed to go. Two weeks later, I started radiation therapy for five days a week and twice on Friday. Each session was about 20 minutes.

A little over a week after radiation began, I lost my sense of taste, my throat felt burned, I had blisters in my mouth and my neck was red. It became difficult to eat, and I started losing weight. I took pain medication and switched to nutrient supplement drinks. According to my doctor, I needed to drink seven a day to get the nutrients needed to avoid having a feeding tube. At first, I thought it would be easy but realized quickly that drinking that much was a challenge. Determined to succeed, I set my alarm for every two hours as a reminder to drink another one.

Three months later on a Friday, I had a PET scan. The radiologist told me the scans showed no signs of cancer. I went home and celebrated with my family. But on Monday, my doctor called and said after further examination, she could see a nodule in my lung. We waited for three more months to see whether the nodule would go away on its own, but the next scan showed the nodule had doubled in size and more spots had shown up in my lung.

This was a low point for me. My wife and I looked at the doctor and asked, "What now?" She gave me two options. I could go on platinum chemotherapy for the rest of my life, which she estimated at about a year, or I could join a clinical trial.

I thought, "Why not?" A clinical trial could work, and my participation alone might help someone else with cancer down the road. It took less than a day to make my decision, and I was the second to last person to join a trial that was testing an immunotherapy.

Every three weeks, I received the immunotherapy treatment by infusion, and surprisingly didn't have any side effects.

To monitor the effectiveness of the immunotherapy, I had regularly scheduled CTs. The first showed that tumors were shrinking. A few months later, no cancer could be detected on a scan. I felt it truly was a miracle! I did not expect to have such amazing results.

I had CTs every four weeks for two years before moving to an annual schedule. The trial continues to follow my progress, but I'm back with my regular oncologist.

Throughout everything, my family surrounded me with support, and I looked into several support groups. It took a few tries, but eventually I found one just right for me. That helped with the mental part of facing head and neck cancer.

I highly recommend vaccinating your children against HPV so they don't have to go through what I did. I never recalled having an HPV infection, so I never knew I had it. Prior to discovering my cancer, we had our two daughters vaccinated. After my experience, we realized our son needed to be, too, and we had him vaccinated as well. Prevention is key! ■

Bill's advice

- **Go to a hospital that specializes in cancer.** They have the expertise you will need.
- **Learn all you can about your diagnosis.**
- **Get a second opinion** so you can make the best decision for you.
- **Be open to joining a clinical trial.**
- **Find emotional support.** For me, the physical part of head and neck cancer was easier than the mental part.

Educate yourself about each potential therapy option

Treatments for head and neck cancers continue to evolve while researchers make progress through clinical trials. New options are giving patients hope for living longer.

THYROID CANCER

The thyroid is a butterfly-shaped gland below the larynx (voice box) in the front of the neck. It produces hormones that help regulate heart rate, body temperature, growth and metabolism. Four parathyroid glands (not shown) are pea-sized organs on the back of the thyroid. They produce hormones that control blood calcium levels.

Thyroid tissues contain two types of cells. Follicular cells produce the thyroid hormone, and parafollicular cells (commonly called C-cells) produce a hormone involved in processing calcium.

Papillary thyroid cancer is the most common of the four primary types of thyroid cancer. It begins in the follicular cells, as does follicular thyroid cancer. Both are called well-differentiated cancers because their cells look similar to healthy thyroid cells when viewed under a microscope. They tend to spread and grow slowly. Medullary thyroid cancer begins in the C-cells and is more aggressive than papillary and follicular thyroid cancer. Anaplastic thyroid cancer is called undifferentiated or poorly differentiated because its cells look very different from healthy thyroid cells. Anaplastic thyroid cancer tends to grow and spread very quickly. It is the most aggressive form of thyroid cancer.

Thyroid cancer is often not accompanied by many symptoms. It is sometimes discovered on imaging scans or other tests performed to diagnose another medical condition.

TREATMENT OPTIONS

Your treatment plan will be based on the type and stage of the thyroid cancer as well as your age, overall health, symptoms, previous treatments and preferences for quality of life. One or more of the following therapies may be recommended.

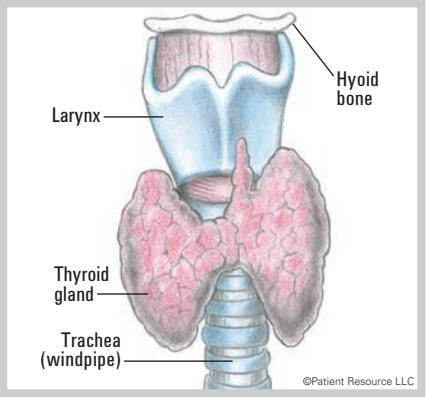
Surgery is the most common treatment for thyroid cancer, and various procedures and techniques may be available.

Lobectomy, also called hemithyroidectomy, may be used in some low-risk cases when only half of the thyroid needs to be removed.

Near-total thyroidectomy is used to remove all but a very small part of the thyroid. Some lymph nodes may also be removed.

Total thyroidectomy removes the entire thyroid gland. As a result, thyroid hormone therapy must be taken because thyroid hormones can no longer be produced in the body. This hormone replacement medication can be taken as a pill. Taking calcium and vitamin D supplements may be necessary if the parathyroid gland function is affected by surgery. Your surgeon may also remove lymph nodes in the neck to see if the cancer has spread.

THYROID ANATOMY



Radioactive iodine treatment can be used to destroy remaining thyroid cells that were not removed by surgery or that have spread beyond what can be removed with surgery. This involves giving radioactive iodine (I-131) in liquid or pill form. The thyroid absorbs almost all iodine that enters the body. The radioactive iodine will concentrate in any remaining thyroid tissue, and the radiation will kill the cancer cells.

This treatment is standard of care for papillary or follicular thyroid cancer that has spread to lymph nodes in the neck or other parts of the body. Radioactive iodine treatment does not work in medullary thyroid cancer or anaplastic thyroid cancer because the cancer cells do not absorb iodine.

Radiation therapy is usually given after surgery as adjuvant therapy and concentrates on targeted cancer cells in a specific area. It is more often used as part of treatment for medullary and anaplastic thyroid cancer. External-beam radiation therapy is used typically for later stage thyroid cancer that has spread to critical areas of the neck, such as the trachea, voice box or esophagus.

➥*Staging tables for thyroid cancer* on page 5.

Drug therapy is systemic therapy that travels throughout the body and may include chemotherapy, hormone therapy or targeted therapy.

Chemotherapy uses drugs to destroy cancer cells by preventing them from growing and dividing. It may consist of a single drug or multiple drugs given in combination. It may also be combined with other types of treatment.

Hormone therapy is used after surgery that removes part of or the whole thyroid. It replaces the hormone needed by the body. It may also slow the growth of remaining differentiated cancer cells.

Targeted therapy drugs are used to slow or stop the progression of disease in certain types of thyroid cancer. Two types of targeted therapy approved for thyroid cancer include tyrosine kinase inhibitors, which block signals needed for tumors to grow, and protein kinase inhibitors, which block proteins needed for cell growth and may kill cancer cells. They may be an option if specific molecular (genetic) abnormalities are found in the tumor. Some of these abnormalities include a neurotrophic tyrosine receptor kinase (*NTRK*) genetic fusion, a *BRAF V600E* gene mutation and *RET* mutation-positive cancers. In some cases, targeted therapy may be used to treat certain types of metastatic thyroid cancer.

Watchful waiting is a strategy of postponing treatment to avoid potential treatment side effects as long as possible. It may be recommended for tumors that appear to be growing very slowly. Your doctor will closely monitor you for signs the cancer has progressed or returned before starting treatment.

THYROID CANCER RESOURCES

American Thyroid Association: www.thyroid.org
Bite Me Cancer: www.bitemecancer.org
HNC Living Foundation: www.hncliving.org
Light of Life Foundation: www.lightoflifefoundation.org
ThyCa: Thyroid Cancer Survivors' Association, Inc.: www.thyca.org
Thyroid Head & Neck Cancer Foundation (THANC): www.thancfoundation.org

➥*Staging tables for throat cancer* on page 4.

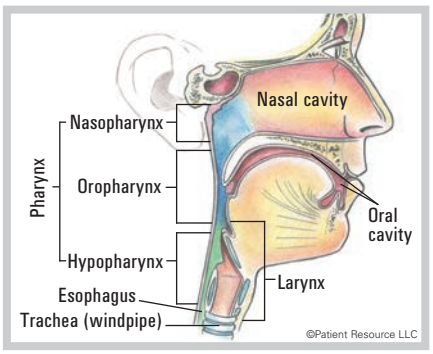
THROAT CANCER

The throat is the more common name for the pharynx (FAYR-inx), a muscular, hollow tube about five inches long. As part of both the respiratory and the digestive systems, it functions as a passageway for air, food and liquid. It begins at the back of the nasal cavity and curves down to meet the esophagus and trachea (windpipe). It is divided into three parts: the nasopharynx, the oropharynx (which includes tonsils) and the hypopharynx.

Throat cancer typically begins in the thin, flat squamous (SKWAY-mus) cells lining the mucous membranes. It may be more specifically referred to by the affected region: nasopharyngeal cancer, oropharyngeal cancer or hypopharyngeal cancer.

Although the oropharynx is at the back of the mouth, oropharyngeal cancer is diagnosed as a throat cancer because the oropharynx is part of the throat. The human papillomavirus (HPV) is linked to most oropharyngeal cancers (see *HPV and Cancer*, page 7). Nasopharyngeal cancer may be caused by the Epstein-Barr virus (EBV), particularly in people of Asian descent. Also known as human herpesvirus 4, EBV is among the most common human viruses.

THROAT ANATOMY



TREATMENT OPTIONS

To develop a treatment plan tailored to you and the type of cancer you have, your doctor will consider the region of the throat where the cancer occurs, whether the cancer is primary or recurrent, and the presence of certain biomarkers related to HPV. Ask your doctor if your diagnosis is HPV+ or HPV-. You will need to look carefully at the staging table head-lines in this guide to ensure you view the infor-mation that applies to your diagnosis as they are staged differently.

Preserving normal function as much as possible will be a priority. Your doctor may suggest one or more of the following options.

Surgery is commonly used to treat oropharyngeal and hypopharyngeal cancers. It is rarely used for nasopharyngeal cancers because the area can be difficult to reach. However, it may be used for nasopharyngeal cancer that does not respond to radiation therapy and to remove lymph nodes or other tissues in the neck. One or more of the following surgeries may be used.

Transoral robotic surgery (TORS) is an option for early-stage oropharyngeal cancers (especially HPV+ tumors). It can be used to remove cancers from the tonsils or the back one-third of the tongue, called the base of tongue. TORS may also be used to treat select, small hypopharyngeal cancers.

Radical tonsillectomy, also known as lateral oropharyngectomy, removes the tonsil as well as a cuff of tissue around the tonsil, including part of the soft palate, pharynx and base of tongue.

Base of tongue resection removes the tumor from the back one-third of the tongue.

Partial pharyngectomy removes part of the pharynx (throat).

Laryngopharyngectomy removes tumors in the hypopharynx. This involves the removal of the larynx (voice box), the vocal folds and pharynx. With this approach, a surgeon reconstructs the pharynx and the surgeon creates a stoma for breathing (see *Adjusting to your stoma*, page 19). Laryngopharyngectomy is typically reserved for large tumors or those that fail nonsurgical treatment.

A *neck dissection* to remove lymph nodes may be performed.

Reconstructive surgery may be recommended to restore function or appearance and replace missing tissue. This surgery would take place at the same time the cancer is being removed (see *Reconstruction & Rehabilitation*, page 19).

Radiation therapy may be given alone or with chemotherapy (chemoradiation) as a first-line treatment for throat cancers in which surgery is not a good option.

External-beam radiation therapy (EBRT) is the most common type of radiation therapy used to treat throat cancers. It includes intensity-modulated radiation therapy (IMRT), stereotactic radiation therapy and proton therapy, with IMRT being the most commonly used and well-researched.

Hyperfractionated radiation therapy, in which the radiation is given in smaller doses but more frequently, may be used for certain cases of advanced throat cancer to improve the way the tumor responds to treatment.

Brachytherapy is a type of internal radiation therapy that may be used in some cases. It surgically implants tiny pellets or rods containing radioactive material in or near the cancer for several days. They are then removed.

Radiation with or without chemotherapy may be recommended following surgery as adjuvant treatment for advanced stage cancers. This therapy may be used to eliminate any remaining cancer cells and to lower the risk of recurrence.

Drug therapy may be used alone or in combination with other therapies.

Chemotherapy given alone may be used to treat cancer that has returned (recurrent) or cancers that are not surgically resectable. In this case, the goal of treatment may be to prevent growth and spread as opposed to cure. It may be given after surgery as adjuvant therapy with radiation therapy (chemoradiation) if the risk for recurrence is high. For nasopharyngeal cancers, additional chemotherapy may be given before starting chemoradiation treatment, also called neoadjuvant chemotherapy. Chemoradiation may be an option for the first treatment used.

Immunotherapy in the form of immune checkpoint inhibitors may be an option for treating certain recurrent or metastatic throat cancers. The doctor will test for the tumor's PD-L1 expression, which may indicate whether the tumor could respond to immunotherapy. If expression is more than 1 percent, the tumor is considered to be PD-L1 positive and immunotherapy alone may be used. If PD-L1 is negative, immunotherapy and traditional chemotherapy are often combined for patients who have recurrent/metastatic cancer.

Targeted therapy drugs may be an option to treat types of throat cancer that contain specific genetic abnormalities, proteins or growth factors. Epidermal growth factor receptor (*EFGR*) inhibitors are approved for oropharyngeal and hypopharyngeal cancer in combination with radiation therapy or chemotherapy.

THROAT CANCER RESOURCES

American Cancer Society: www.cancer.org
Laryngeal and Hypopharyngeal Cancer
Nasopharyngeal Cancer
Oral Cavity and Oropharyngeal Cancer

Centers for Disease Control (CDC): www.cdc.gov
Human Papillomavirus (HPV) and Cancer

Head & Neck Cancer Alliance: www.headandneck.org

National Cancer Institute: www.cancer.gov
Hypopharyngeal Cancer Treatment
Nasopharyngeal Cancer Treatment
Oropharyngeal Cancer Treatment

➥*Staging tables and illustrations for oral cancer* on page 2.

ORAL CANCER

The oral cavity area (known as the mouth) includes the lips, gums, lining inside the lips and cheeks, hard palate (front part of the roof of the mouth), the front two-thirds of the tongue, the floor of the mouth underneath it, and the retromolar trigone, which is the small space behind each wisdom tooth.

More than half of all head and neck cancers begin in the oral cavity. Oral cancers usually develop in the thin, flat squamous (SKWAY-mus) cells lining moist surfaces inside the mouth and are called squamous cell carcinoma. Cancers in the back of the mouth, including the base of the tongue, rear roof of the mouth (soft palate) and tonsils, are considered a type of throat (oropharyngeal) cancer.

Because the symptoms of oral cancer can also signal many other conditions, they are frequently diagnosed at a late stage. However, dentists typically screen for cancer at regular six month or annual appointments.

It is very important for you and your doctor to have detailed discussions about the benefits, risks and potential side effects and late effects of every treatment, including quality-of-life issues.

TREATMENT OPTIONS

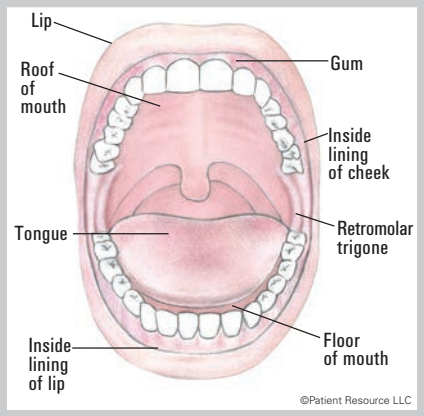
As you discuss your treatment plan with your doctor, keep in mind that treating oral cancer may affect the ability to speak and eat normally and may alter appearance. As a result, you are encouraged to discuss reconstructive options as well. Many surgeons that remove head and neck cancer are also trained in reconstruction and can expertly perform both parts of the surgery (see *Reconstruction & Rehabilitation,* page 19).

Your treatment plan may include one or more of the following options.

Surgery is typically the recommended treatment for oral cavity cancers. It is performed to remove small, early-stage tumors of the lip, gums, roof of the mouth, front of the tongue, floor of the mouth and inside the cheeks. It may also be used to remove larger tumors and those that have metastasized (spread) to nearby tissue or lymph nodes in the neck. The goal of surgery is to remove the tumor; however, your surgeon will also focus on preserving as much function as possible. Various procedures and techniques may include the following.

Tumor resection removes the tumor and a margin of healthy tissue surrounding it.

ORAL ANATOMY



Glossectomy removes all or part of the tongue. A partial glossectomy removes less than half of the tongue, a hemiglossectomy removes half of the tongue, and a subtotal or total glossectomy removes most or all of the tongue.

Maxillectomy removes all or part of the hard palate.

Mandibulectomy removes all or part of the jawbone.

Composite resection is common in treating advanced oral cancers. It may involve the removal of multiple areas affected by cancer, such as part of the jaw, tongue and floor of the mouth.

Mohs micrographic surgery may be recommended for some types of lip cancer. After removing the tumor, the surgeon removes a tiny fragment of tissue that had surrounded it and examines it under a microscope. The process is repeated until clear margins are seen. This type of procedure is performed by a dermatologist.

Neck dissection removes some of the lymph nodes in the neck when the cancer has spread to the area or if there is a significant risk it will spread to the lymph nodes.

Reconstructive procedures may be recommended to repair or replace removed areas, improve the ability to eat and speak, and help restore appearance as much as possible (see *Reconstruction & Rehabilitation*, page 19.

Radiation therapy in the form of external-beam radiation therapy or internal radiation therapy (brachytherapy) may be recommended. It may be used alone if you are not a candidate for surgery (due to other medical problems or the extent of the cancer). This does not cure the cancer but may slow down the growth and spread, and alleviate symptoms.

Radiation is typically used after surgery as adjuvant therapy to destroy remaining cancer cells and reduce the risk of the cancer recurring. Radiation therapy may also be used alone or with chemotherapy (chemoradiation) for cancer that has a higher risk of recurring.

Radiation therapy to the oral cavity can affect your teeth. Before beginning this type of treatment, you will be required to have a thorough dental exam to address existing problems with a dentist experienced in treating people with cancer (see *Dental & Oral Side Effects*, page 17). If you smoke, be aware that research indicates radiation therapy is more effective in patients who have stopped smoking before beginning treatment.

Drug therapy may be used alone or with other therapies.

Chemotherapy can be used for oral cavity cancer if you are not a candidate for surgery. This can be given with the goal of slowing down the growth and spread of the cancer. It is more commonly used as adjuvant treatment following surgery if your cancer has aggressive features and a higher risk of returning.

Immunotherapy in the form of immune checkpoint inhibitors may be part of your treatment plan if you have recurrent or metastatic oral cancer. The doctor will test for the tumor's PD-L1 expression, which may indicate whether the tumor could respond to immunotherapy. If expression is more than 1 percent, the tumor is considered to be PD-L1 positive and immunotherapy alone may be used. If PD-L1 is negative, immunotherapy and traditional chemotherapy are often combined for patients who have recurrent/metastatic cancer.

Targeted therapy may be an option to treat types of oral cancer that contain specific genetic abnormalities, proteins or growth factors. Targeted therapy in the form of epidermal growth factor receptor (*EGFR*) inhibitors may be used in combination with radiation therapy. Targeted therapy drugs may be given alone or in combination with chemotherapy or radiation therapy.

ORAL CANCER RESOURCES

American Cancer Society: www.cancer.org
Oral Cavity and Oropharyngeal Cancer

American Society of Clinical Oncology: www.cancer.net
Oral and Oropharyngeal Cancer

National Cancer Institute: www.cancer.gov
Lip and Oral Cavity Cancer Treatment

Oral Cancer Awareness Foundation (OrCA): www.4orca.org

The Oral Cancer Foundation: www.oralcancerfoundation.org

Support for People with Oral and Head and Neck Cancer (SPOHNC): www.spohnc.org

➥*Staging tables for sinus & nasal cancer* on page 3.

SINUS & NASAL CANCER

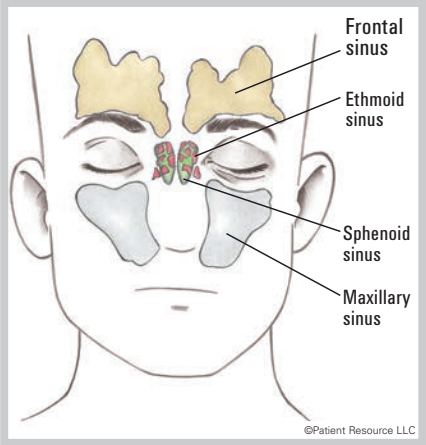
The sinuses and the nasal cavity work together to filter, warm and moisten the air you breathe before it reaches your lungs. Cells in the sinuses make mucus to keep your nose from drying out.

You have four paranasal sinuses: in the hollow spaces in the bones around your nose; behind your cheekbones; above, below and between your eyes; and in the center of your skull. Named for the bones that surround them, they are the frontal, ethmoid, sphenoid and maxillary sinuses.

The nasal cavity is a continuation of the nostrils into your nose. It extends to the back of your nose to the nasopharynx above the soft palate. The nasal cavity is divided into a right and left side by your septum.

Cancer typically develops in thin, flat squamous (SKWAY-mus) cells lining the sinuses and nasal cavity. The most common place for this type of cancer to occur is in the maxillary sinuses.

SINUS & NASAL ANATOMY



TREATMENT OPTIONS

Based on the stage of the disease and your age, overall health, symptoms, previous treatments and preferences for quality of life, one or more of the following therapies may be recommended.

Surgery is frequently used to remove any stage of sinus and nasal cancer. It may be the only treatment needed for early-stage cancer. During surgery, the cancer will be removed along with an area of normal tissue around it and some surrounding bone or other nearby tissues. It may also be used if the cancer is found in the nasal cavity. If the tumor is found in the septum (dividing wall of the nose), the whole septum may be removed.

Many types of surgery are available. Your doctor will consider the location and stage of your cancer to choose the appropriate surgery for you.

Many early sinus and nasal cancers can be removed endoscopically (with a thin, lighted camera and instruments designed to pass through the nose) and do not require incisions on the face. However, many advanced tumors will require external incisions for adequate removal.

Medial maxillectomy may be used to treat a tumor in the side wall of the nasal cavity and may involve removing the side wall.

Maxillectomy may be done if the tumor has grown into the maxillary sinus. A maxillectomy may involve removal of bone from the roof of the mouth, part or all of the eye socket, part of the cheekbone, upper teeth and/or the bony part of the upper nose. In very advanced cancers that involve the eye itself, an exenteration, which includes removal of the eye, may be necessary.

Endoscopic ethmoidectomy may be used if the tumor is small and found only in the ethmoid sinuses. This involves the use of an endoscope (a thin, lighted camera) to reach the ethmoid sinuses through the nose. In some cases, it is necessary to make an incision (cut) between the nasal bridge and the eye to reach the ethmoid sinuses. This is called an *external ethmoidectomy*.

Craniofacial resection may be done if the cancer is found in the ethmoid sinuses, frontal sinuses and/or the sphenoid sinuses. This surgery is more extensive than a maxillectomy because it can include removal of the upper parts of the eye socket and front of the skull base.

A neck dissection (removal of lymph nodes in the neck) is often performed, regardless of whether the cancer is in the sinus or nasal cavity.

- A selective neck dissection involves removal of lymph nodes from a limited area of the neck.
- A modified radical neck dissection involves removal of most of the lymph nodes on one side of the neck between the jawbone and collarbone, in addition to some muscle and nerve tissue.
- A radical neck dissection involves removal of nearly all of the lymph nodes on one side of the neck and even more muscle, nerves and veins.

Reconstructive surgery may be needed after the primary surgery to restore functional ability and/or appearance. Missing tissue, skin or bone may be replaced during this surgery (see *Reconstruction & Rehabilitation,* page 19).

Radiation therapy may be the main treatment if your general health is too poor for surgery. It is generally used for cancers in the sphenoid sinuses because these areas are difficult to reach surgically. It can be used after surgery as adjuvant treatment. It may also be combined with chemotherapy (chemoradiation). Radiation delivery methods vary by type and stage of cancer.

External-beam radiation therapy is delivered by a machine outside of the body. Types of this treatment include three-dimensional conformal radiation therapy (3D-CRT) and intensity-modulated radiation therapy (IMRT).

Internal radiation therapy, also known as brachytherapy, may be used.

Proton therapy uses protons instead of X-rays and may benefit some patients depending on the location of the tumor.

Drug therapy may be given alone or in combination with other therapies.

Chemotherapy may be given before surgery as neoadjuvant therapy or after surgery as adjuvant therapy. It may be combined with radiation therapy (chemoradiation). Chemotherapy for sinus and nasal cancers is usually given when the disease is advanced.

Immunotherapy in the form of immune checkpoint inhibitors may be part of your treatment plan if you have a certain type of recurrent or metastatic sinus and nasal cancer. The doctor will test for the tumor's PD-L1 expression, which may indicate whether the tumor could respond to immunotherapy. If expression is more than 1 percent, the tumor is considered to be PD-L1 positive and immunotherapy alone may be used. If PD-L1 is negative, immunotherapy and traditional chemotherapy are often combined for patients who have recurrent/metastatic cancer.

Targeted therapy may be an option to treat certain types of sinus and nasal cancer. Targeted therapy in the form of epidermal growth factor receptor (*EGFR*) inhibitors may be used in combination with radiation therapy. Targeted therapy drugs may be used with or without chemotherapy and after surgery for advanced cancers.

SINUS & NASAL CANCER RESOURCES

American Cancer Society: www.cancer.org
Nasal Cavity and Paranasal Sinus Cancer

American Society of Clinical Oncology: www.cancer.net
Nasal Cavity and Paranasal Sinus Cancer

Head and Neck Cancer Alliance: www.headandneck.org

HNC Living Foundation: www.hncliving.org

National Cancer Institute: www.cancer.gov
Paranasal Sinus and Nasal Cavity Cancer Treatment

➥*Staging tables for salivary gland cancer* on page 3.

SALIVARY GLAND CANCER

Salivary glands produce saliva to help you swallow, chew and digest food and keep your mouth and throat moist. Saliva contains enzymes that begin the process of breaking down food and antibodies that help prevent mouth and throat infections.

Your head and neck contain major and minor salivary glands, with a set of three major glands on each side of your face. The parotid glands are the largest of the major glands and are located just in front of each ear. The submandibular glands below your mandible (jawbone) are smaller. The sublingual glands under the mouth floor are the smallest. You also have hundreds of microscopic minor salivary glands.

Tumors most often occur in the parotid glands. Tumors in the minor salivary glands are not common; however, they are more likely to be malignant when they occur.

TREATMENT OPTIONS

Your doctor will consider the subtype, stage and grade of your cancer when developing a treatment plan for you. Multiple subtypes have been identified in salivary gland cancer. Some are benign, and others are cancerous.

Treatment for salivary gland tumors is also based on the grade of the cancer. In general, the lower the tumor grade, the better the prognosis (outlook).

Treatment to salivary glands can impact your speech, chewing and swallowing. Talk with your doctor about the benefits and risks as well as the potential side effects and late effects of each type of therapy before making decisions.

One or more of the following options may be part of your treatment plan.

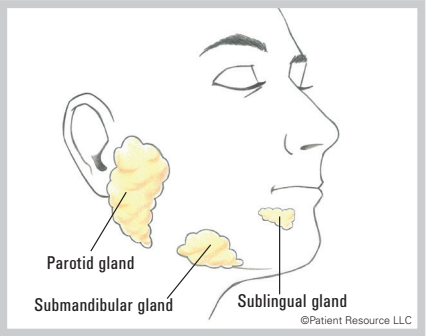
Surgery is the most common treatment for salivary gland cancer to remove the tumor and surrounding tissue. More than one surgery may be needed to treat the cancer and to repair the area (see *Reconstruction & Rehabilitation,* page 19). One of the following procedures may be used.

Superficial parotidectomy may be used to remove cancer in the outside part of the parotid gland, also known as the superficial lobe. This involves removing the lobe.

Total parotidectomy to remove the entire parotid gland may be used if the cancer extends to deeper tissues. Removal of the facial nerve may be required, which would affect facial movement.

Other surgical procedures include endoscopic surgery, removal of the submandibular or sublingual glands, and a lymph node dissection (lymphadenectomy) to remove lymph nodes in the neck.

MAJOR SALIVARY GLAND ANATOMY



Radiation therapy may be recommended for intermediate or high grade or advanced salivary gland cancers after surgery (adjuvant therapy) to kill remaining cancer cells. If surgery is not an option, radiation may be the main treatment, but radiation treatment may not be effective alone against some salivary gland tumors. It is sometimes used to manage symptoms of pain, bleeding or trouble swallowing and in cases of recurrent or advanced salivary gland cancer. Two main types of radiation may be used.

External-beam radiation therapy (EBRT) uses a machine outside the body to send radiation toward the cancer. Different types of EBRT are available and include intensity-modulated radiation therapy and proton therapy, which uses charged particles called protons.

Internal radiation therapy, also called brachytherapy, uses a radioactive substance sealed in needles, seeds, wires or catheters that are placed directly into or near the cancer.

Radiation therapy may also be combined with chemotherapy, known as chemoradiation.

Drug therapy may be recommended for some cases.

Chemotherapy may be used to treat late-stage salivary gland cancer or to treat symptoms.

Immunotherapy in the form of immune checkpoint inhibitors may be used to treat recurrent or metastatic salivary gland cancer that has stopped responding to chemotherapy. The doctor will test for the tumor's PD-L1 expression, which may indicate whether the tumor could respond to immunotherapy. If expression is more than 1 percent, the tumor is considered to be PD-L1 positive and immunotherapy alone may be used. If PD-L1 is negative, immunotherapy and traditional chemotherapy are often combined for patients who have recurrent/metastatic cancer.

Targeted therapy may be an option for some subtypes of salivary gland cancer through clinical trials. This type of personalized treatment attacks the source of a tumor's growth, focusing on certain parts of cells and the signals that cause them to grow unchecked or keep from dying. These signals are often sent by proteins called tyrosine kinases. In salivary gland cancer, some of these drugs also target specific genes or molecular alterations, including neurotrophic tyrosine receptor kinase (*NTRK*), human epidermal growth factor receptor-2 (*HER2*) and epidermal growth factor receptor (*EGFR*).

SALIVARY GLAND CANCER RESOURCES

American Cancer Society: www.cancer.org
Salivary Gland Cancer

American Society of Clinical Oncology: www.cancer.net
Salivary Gland Cancer

National Cancer Institute: www.cancer.gov
Salivary Gland Cancer Treatment

LARYNGEAL CANCER

The larynx (LAYR-inx) is often called the voice box because it holds the vocal cords. This short, hollow organ in the lower part of your throat is a passageway to the lungs. It is involved in functions that help you talk, breathe and swallow. It enables you to speak and protects your vocal cords with cartilage walls that form your Adam's apple. The larynx helps you breathe as part of the respiratory system. When you swallow, a tissue flap called the epiglottis (eh-pih-GLAH-tis) covers your trachea (windpipe) to keep food and liquid from entering your lungs.

Only two inches long, the larynx has three parts. The vocal cords are in the middle part called the glottis. Above is the supraglottis, and below is the subglottis, which ends at the top of your trachea.

Cancer of the larynx is called laryngeal (layr-en-JEE-ul) cancer. It most often first develops in the organ's moist lining in thin, flat squamous (SKWAY-mus) cells and is called squamous cell carcinoma.

Before treatment, your doctor will evaluate your voice, breathing and swallowing functions, as well as thoroughly discuss the benefits and risks of each treatment option and the impact potential side effects and late effects may have on your quality of life.

TREATMENT OPTIONS

The primary goal of your health care team will be to focus on removing, destroying or shrinking the tumor and preserving (as much as pos-

➥*Staging tables for laryngeal cancer* on page 5.

sible) your larynx because it affects your ability to speak, eat and breathe.

One or more of the following treatments may be used.

Surgery is a common treatment for early glottic cancers and locally advanced T4a tumors. It is less common to treat T2-T3 tumors surgically. The following procedures, beginning with least invasive, may be recommended.

Vocal cord stripping removes the superficial layers of tissue on the vocal cords. This technique can be done for a biopsy sample or to treat pre-cancers and early-stage cancers of the vocal cords. Most people can eat, speak and breathe normally after recovery.

Endoscopic resection is performed through an endoscope (a thin, lighted camera) and is used to remove cancer that is confined to the vocal cords or is early stage.

Transoral laser microsurgery (TLM) avoids the need for neck incisions and may be used to remove laryngeal cancers that are superficial or limited in extent.

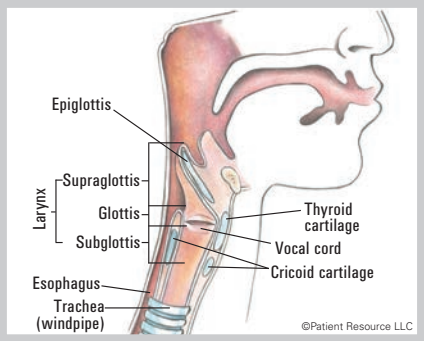
Cordectomy removes all or part of a vocal cord and may be used to remove small cancers of the glottis. Removing part of a vocal cord typically causes permanent hoarseness and may cause temporary swallowing difficulties.

Laryngectomy removes all or part of the larynx. Your ability to speak after recovering from surgery depends on how much of the larynx is removed.

- Supraglottic laryngectomy removes the part of the larynx above the vocal cords and may be used when tumors are confined to the supraglottis. Speech therapy will be necessary after recovery, and the effect on speech varies.
- Vertical hemilaryngectomy may be used to treat cancers of the vocal cords. It involves removing one vocal cord and leaving the other intact. You may still have some ability to speak, but your speech will change.
- Supracricoid laryngectomy removes a large part of the larynx, including both vocal cords. Your ability to speak is preserved, although how you speak will change.

All of the above types of laryngectomy also affect your ability to safely swallow. Most patients require at least a temporary feeding tube during recovery. Many patients will also need a tracheostomy tube after surgery that may be removed once everything is healed and the swelling has resolved. Patients with underlying lung problems, such as COPD or emphysema, are generally not candidates for this type of surgery.

LARYNX ANATOMY



Total laryngectomy removes the entire larynx and vocal cords. This surgery permanently separates the trachea (windpipe) from the esophagus and then attaches the trachea to a hole created in the front of the neck called a stoma (see *Adjusting to your stoma*, page 19). The stoma is the new airway to breathe through instead of breathing through your mouth and nose. A total laryngectomy may be used to treat advanced or recurrent cancers when there are no other viable options. Following recovery, you must learn new ways to communicate because normal speech is no longer possible. Most of the time, you will be able to swallow after you heal from surgery. If your doctor performs a laryngectomy, you may also have reconstructive surgery (see *Reconstruction & Rehabilitation*, page 19).

A *neck dissection* to remove some lymph nodes in your neck may be recommended. Your doctor will consider the exact location and stage of your tumor.

Radiation therapy with or without chemotherapy is an option for many patients and is often called organ preservation treatment — meaning you keep your larynx. Radiation is typically an option for patients with T1-T3 cancers. Radiation may also be used for patients with more advanced tumors that are not candidates for surgery.

If radiation therapy is a part of your treatment plan, it is recommended you have a pretreatment evaluation by an oncologic dentist and speech pathologist before receiving radiation therapy (see *Dental & Oral Side Effects*, page 17). Smoking can interfere with the effectiveness of this treatment, so it is recommended that you stop before beginning therapy.

External-beam radiation therapy (EBRT) is most commonly used to treat laryngeal cancer. It is typically given once daily for a set amount of time. Types of EBRT include three-dimensional conformal radiation therapy (3D-CRT) and intensity-modulated radiation therapy (IMRT). Another type, hyperfractionated radiation therapy, involves treatments containing small doses of radiation given more than once a day. It is given over the same period of time as standard radiation therapy.

Chemoradiation therapy combines radiation therapy with chemotherapy for more advanced cancers. They are frequently used together because chemotherapy often enhances the effectiveness of radiation therapy. It may be used if organ preservation surgery is not an option.

Radiation with or without chemotherapy may be recommended for advanced stage cancers to eliminate any remaining cancer cells and to lower the risk of recurrence.

Drug therapy may be used alone or in combination with other therapies.

Chemotherapy may be used alone. Chemoradiation therapy may be used after surgery as adjuvant therapy to decrease the likelihood of cancer recurrence. It may be the primary treatment for some cases of laryngeal cancer. If no traces of the tumor remain, surgery may not be necessary.

Immunotherapy in the form of immune checkpoint inhibitors may be used to treat recurrent or metastatic laryngeal cancer if surgery or chemoradiation is not an option. The doctor will test for the tumor's PD-L1 expression, which may indicate whether the tumor could respond to immunotherapy. If expression is more than 1 percent, the tumor is considered to be PD-L1 positive and immunotherapy alone may be used. If PD-L1 is negative, immunotherapy and traditional chemotherapy are often combined for patients who have recurrent/metastatic cancer.

Targeted therapy may be used to treat types of laryngeal cancer that contain specific genetic abnormalities, proteins or growth factors. Epidermal growth factor receptor (*EFGR*) inhibitors are approved for use in combination with radiation therapy for laryngeal cancer that has not spread. *EGFR* inhibitors may be used with chemotherapy for metastatic laryngeal cancer. ■

LARYNGEAL CANCER RESOURCES

American Society of Clinical Oncology:
www.cancer.net
Laryngeal and Hypopharyngeal Cancer

American Speech-Language-Hearing Association:
www.asha.org
Laryngeal Cancer

Head and Neck Cancer Alliance:
www.headandneck.org

International Association of Laryngectomees:
www.theial.com

National Cancer Institute: www.cancer.gov
Laryngeal Cancer Treatment

Plan ahead for side effect management

Before treatment begins, talk with your medical team about possible side effects and what to do if they occur. The most important thing to remember is to communicate honestly about how you feel, both physically and emotionally. The sooner you share your concerns, the quicker they can be managed.

Your health care team relies on a group of services known as supportive care. Supportive care is also known as palliative care and is often confused with hospice care. They are not the same thing. Hospice is reserved for end-of-life care, and supportive care addresses the physical, emotional, practical, spiritual, financial and family-related challenges associated with cancer. Many people use it to manage physical side effects, but other resources are available: nutrition, fitness, mental health, spirituality, physical/occupational therapy, speech therapy and more. Your family members, caregivers and others close to you can also benefit from this support.

POTENTIALLY SEVERE SIDE EFFECTS

Though serious side effects are rare, they can occur with certain treatments. Ask your doctor whether the therapies in your treatment plan put you at risk and, if so, how to identify the symptoms and when to seek emergency care. Report symptoms immediately.

- Infection can occur as a result of a low white blood cell count (neutropenia) and other factors.
- Immune-related adverse events (irAEs) may occur if the immune system becomes overstimulated by treatment and causes inflammation in one or more organs or systems in the body. Some irAEs can develop rapidly, becoming severe and even life-threatening without immediate medical attention.
- Cytokine release syndrome can occur if immune cells affected by treatment rapidly release large amounts of cytokines into the bloodstream. Symptoms may include headache, fever, nausea, rash, low blood pressure, rapid heartbeat and difficulty breathing.
- Infusion-related reactions most frequently occur with intravenous (IV) treatments, usually soon after exposure to the drug.
- Tumor lysis syndrome (TLS) may occur after the treatment of a fast-growing cancer, and with some types of drug therapy. TLS can potentially damage the kidneys, heart, liver or other organs.

COMMON SIDE EFFECTS

Every person responds to treatment differently. Head and neck cancer treatments, used alone or in combination, often cause side effects (see Table 1).

Late effects, which are side effects that develop weeks, months or years after treatment ends, may occur. Some disappear over time, while others are permanent.

SURROUND YOURSELF WITH SUPPORT

You can expect to feel a range of emotions, from anger and anxiety to isolation and depression. This is normal, especially because your illness affects a part of your body that is always on display. It can affect every area of your life, including intimacy, career and socializing. It is essential to share your feelings with people who understand what you are going through.

Support groups for head and neck cancer survivors are available in person and online. Participants openly share what they have learned from challenges with treatments, in their relationships or careers and in other areas. Some groups offer one-on-one buddy programs or peer-to-peer support that pairs you with another person who shares your diagnosis.

Advocacy groups, national organizations and wish-fulfillment organizations are also available. Some organizations specifically help head and neck cancer survivors manage the unique financial challenges of treatment. Through donations, grants and volunteers, patients are able to move forward with treatment and recovery with much-needed help in a variety of areas, from access to liquid nutrition and transportation to medical appointments and dental prosthetics. ■

TABLE 1

SOME COMMON SIDE EFFECTS OF HEAD AND NECK CANCER TREATMENT

Side Effect	Symptoms
Anemia	Low energy, weakness, dizziness, light-headedness, shortness of breath, rapid heartbeat
Bone loss and pain	Weakened bone caused by the cancer or treatment
Chemo brain	Brain fog, confusion and/or memory problems
Constipation	Difficulty passing stools or less frequent bowel movements compared to your usual bowel habits
Decreased appetite	Eating less than usual, feeling full after minimal eating, not feeling hungry
Diarrhea	Frequent loose or watery bowel movements that are commonly an inconvenience but can become serious if left untreated
Difficulty swallowing	Also called dysphagia; may include painful swallowing
Fatigue	Tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person has
Fever	Raised body temperature that could signal an infection
Hair loss (alopecia)	Hair loss on the head, face and body
Headache	Pain or discomfort in the head
Lymphedema	Swelling where lymph nodes have been removed or damaged
Nausea and vomiting	The feeling of needing to throw up and/or throwing up
Neuropathy	Numbness, pain, burning sensations and tingling, usually in the hands or feet at first
Neutropenia	Low white blood cell count that increases the risk of infection
Pain	Pain and aches that occur in the muscles, bones, tendons, ligaments or nerves
Respiratory problems	Shortness of breath (dyspnea) with or without cough, upper respiratory infections
Skin reactions	Rash, redness and irritation or dry, flaky or peeling skin that may itch
Thrombocytopenia	Low number of platelets in the blood, which can lead to bruising and bleeding
Trismus	Jaw stiffness, reduced ability to open mouth wide, pain opening and closing mouth
Weight changes	Gaining or losing weight unintentionally

Managing oral complications through treatment and beyond

Head and neck cancer is treated with surgery, radiation therapy, drug therapy and other medications. Used alone or in combination, these treatments can result in side effects that range from minor to severe. Because treatment to the head and neck can affect breathing, speaking, eating, swallowing and other vital functions, it is critical to know the side effects to expect and how to prevent them from making these functions even more challenging.

BEFORE TREATMENT

Some complications can be prevented by seeking dental care before treatment. The goal is to treat any existing problems so they do not become worse during treatment. This may include having some teeth extracted.

Find a dentist who specializes in treating people who have oral complications from cancer treatment.

AFTER TREATMENT BEGINS

Check your mouth daily. Many problems can be seen or felt. The sooner you notice them, the quicker they can be managed.

Following are some common dental and oral side effects. Some can be attributed to specific treatments (see Table 1).

Dry mouth, or xerostomia (zeer-oh-STOH-mee-uh), occurs when the salivary glands do not produce enough saliva because of damage from radiation therapy, chemotherapy or other medications. This is uncomfortable and increases your risk of both oral infections and tooth decay.

Infections are a greater risk for many reasons related to cancer treatments, including damage to mouth tissues, a lower white blood cell count (neutropenia) and a weakened immune system. These therapies, as well as steroids and antibiotics, can also alter the balance of bacteria in your mouth, making you susceptible to a fungal infection commonly called thrush. Confirm the symptoms that require a call to the doctor.

Jaw and/or **mouth stiffness** can be caused by surgery, radiation therapy or even stress. Often painful, it can interfere with healing and lead to malnutrition. Prevention is very important because the condition is difficult to treat. Ask your health care team about jaw muscle exercises, such as opening your mouth as far as possible without pain, then closing it to repeat. Medication may be used to relax your jaw and mouth muscles.

Mouth pain and soreness can make eating, chewing and swallowing difficult, preventing you from getting adequate nutrition. Pain can also slow the healing process. Controlling mouth pain is essential to the success of your treatment as well as your quality of life.

Oral mucositis (myoo-koh-SY-tis), or mouth sores, can occur when mucous membranes become inflamed. This is common with chemotherapy and is also possible with radiation therapy. Tiny sores begin in the mouth lining and become red, burn-like or ulcer-like sores. They can make it difficult to eat, drink or swallow.

Swallowing difficulties, called dysphagia (diz-FAY-jee-uh), and painful swallowing can make getting adequate nutrition a real challenge. Your health care team will examine you to determine the underlying cause, which could be related to treatment or to the cancer itself. You will likely be referred to a speech therapist to learn techniques that will help make swallowing easier. Drinking thickened fluids may also help. Call your doctor right away if you cough or choke while eating.

Taste changes are common for people receiving radiation therapy to the head or neck because cells in the salivary glands and/or taste buds can become damaged. Your sense of smell may also be affected. The condition generally lessens within a few months after treatment ends.

Tooth decay and **gum disease** are likely to occur. It is important to find a dentist experienced in treating cancer survivors. Discuss how frequently you should schedule routine dental visits from now on. ■

TABLE 1

ORAL SIDE EFFECTS BY TREATMENT TYPE

Treatment Type	Side Effects
Chemotherapy	Bleeding, dehydration, dry mouth, infection, inflammation, malnutrition, oral mucositis, pain and soreness, swallowing difficulties, taste changes
Radiation therapy (in the area where the radiation beams are aimed)	Breakdown of bone or tissue, dehydration, dry mouth, growth of fibrous tissue or muscle, gum disease, infection, inflamed mucous membranes, jaw and mouth stiffness, malnutrition, oral mucositis, pain and soreness, swallowing difficulties, taste changes, tooth decay
Surgery	Infection, jaw and mouth stiffness, pain and soreness, swallowing difficulties

PRACTICAL TIPS FOR A HEALTHY MOUTH

▸ ***Connect with other head and neck cancer survivors to learn how they manage dental and oral side effects. These suggestions may also help.***

1. Find a dentist who is experienced with treating head and neck cancer patients, and schedule regular visits.
2. Brush your teeth, tongue and gums with a soft-bristled toothbrush using a fluoride toothpaste every four hours and at bedtime.
3. Use unscented lip balm to keep your lips from drying and cracking. Avoid oil-based products.
4. Wear dentures that fit properly, and leave them out whenever possible to expose your gums to air. Brush and rinse dentures every day.
5. Avoid spicy, acidic, crunchy and sugary foods.
6. Sip water often and keep a water bottle with you.
7. Use alcohol-free mouthwash to avoid irritating your mouth lining.
8. Floss daily, unless bleeding occurs.
9. Rinse your mouth several times a day and after eating with a mixture of 1 tablespoon of baking soda in 1 quart of warm water.
10. Avoid alcohol and tobacco products.

Take control of your personal nutrition strategy

Your head and neck cancer treatment may significantly affect how you eat and, in turn, how your body gets the key nutrients and fluids it requires to heal and help you maintain your daily activities. Learn about the unique nutrition challenges ahead and the options you have to get the nutrients your body needs.

Start by meeting with a registered dietitian. This person will be a valuable resource for you throughout treatment and beyond. If your health care team does not have a dietitian on staff, ask for a referral.

Next, learn all aspects of your treatment plan. It may include more than one type of treatment, so make sure you are aware of all potential side effects. For example, surgery can cause physical changes that affect your ability to eat. Radiation therapy and some drug therapies target cancer cells along with healthy cells, which often results in side effects, such as mouth sores, appetite loss and nausea, that can make it difficult for you to get the nutrients you need. A key goal will be to focus on preventing your treatment from being interrupted due to malnutrition.

Connect with a speech pathologist. Along with helping you learn to speak again, this person recommends how to confidently resume eating in public. Part of healing is returning to the things you love doing that you have long missed. When you are ready to get back out there, these suggestions may make dining out more comfortable and enjoyable:

- Browse restaurants online and choose one that offers selections you can eat comfortably.
- Preselect your entrée before you go.
- Call ahead to reserve a table that allows for more privacy.
- Ask that your water glass be kept full.
- Request half the meal to be served and the remainder placed in a carryout container. Have that portion precut into small pieces.
- Promote conversations that aren't related to cancer to make it a fun social outing for everyone.

HOW YOU WILL GET THE NUTRITION YOU NEED

As you heal, the consistency of the foods you consume will gradually change, with the goal of getting back to solid foods. Every person reacts to treatment differently and will move at their own pace. Your dietitian will work with you to ensure you are getting the right nutrients every step of the way. These are generally the types of diets that are available.

Regular diet: Selections from all the food groups.

Soft diet: Foods that are easier to chew and swallow. They can often be easily mashed with a fork.

Puréed or **blenderized diet:** Foods that are puréed in a blender so they are easy to swallow.

Full liquid diet: Foods that are smooth and can be poured. You may use a thickening agent to adjust the thickness of the liquid for easier swallowing. Swallow therapy may help.

Clear liquid diet: Liquids that are easily digested and generally see through. Although clear liquids will not offer the nutrition needed to sustain you, they can be used to quench your thirst and may help relieve treatment side effects.

Nutritional supplements: These can accompany any type of diet to help maintain the nutritional status your body needs.

Enteral (EN-teh-rul) nutrition: Also referred to as tube feeding, this is a temporary or permanent method for getting your necessary nutrients. It may be your only source of nutrition or it may supplement the food you eat by mouth. Though the idea of tube feeding may concern you, keep in mind the extra nutrition will help you keep your strength up during treatment.

A tube is placed directly through your abdomen and into the stomach or intestine. The formula that goes into the feeding tube is a liquid mixture to maintain strength and fuel the healing process. It is delivered through the tube directly into your gut. It can be given in several "meals" throughout the day (also called bolus feeding), or a specific amount can be delivered over a certain amount of time through a special pump.

In the hospital, your health care team will manage this for you. If you need to continue (or begin) this type of feeding at home, you will be trained on the process. Medications can sometimes be given through the feeding tube. Ask your doctor or pharmacist about this option. Contact your health care team immediately if you have any of these problems: leaking from the tube, discomfort at the tube site, digestive problems or continued weight loss despite taking in the appropriate amount of formula.

Even though you may not be using your mouth to eat as much or at all, brushing your teeth, flossing and caring for your gums should remain a priority. ■

HELPFUL HINTS

When side effects prevent you from taking in enough nutrition, these suggestions may help.

For Appetite Loss

- Eat smaller portions more frequently.
- Carry snacks with you so you can eat when you are hungry.
- Add extra calories by using butter, oil, mayonnaise, sauces, dressing, gravy, honey, jam, cheese and nut butters.
- Add extra protein by eating poultry, meat, fish, eggs, yogurt, cheese and beans.
- Drink high-calorie and high-protein juices, shakes and smoothies.
- Exercise to help stimulate appetite.

For Dehydration

- Keep a water bottle with you at all times.
- Use a straw to make drinking easier.

For Nausea

- Eat small snacks frequently.
- Keep ginger tea and ginger chews on hand. Ginger can help reduce nausea.
- Ask a member of your health care team about medications that may help relieve nausea.
- Stay hydrated.

For Taste Changes

- Use a non-alcohol-based mouthwash.
- Use plastic utensils instead of metal ones.
- Add extra flavor to foods with spices.
- Use sugar-free lemon drops, gum or mints.

Recapturing functionality and restoring self-esteem

Depending on the type of cancer and treatment you experienced, you may need reconstructive surgery. You are encouraged to consult with a skilled surgeon who is experienced in head and neck reconstruction about the procedures that may help you perform any impaired vital functions as well as options for restoring your appearance, if needed.

Be aware that reconstruction may require more than one procedure, often not yielding immediate results. Certain organizations are dedicated to contributing financially to help head and neck cancer survivors live fully during and after treatment (see *Assistance & Support*, page 23).

One or more of the following procedures may be used.

Dental rehabilitation. This may be recommended if your upper or lower jaw (maxilla or mandible) and teeth are removed. Prosthetic (artificial) teeth can improve appearance and help you eat more normally. This may include dentures or dental implants.

Flap surgery. When treatment involves surgically removing a significant amount of tissue or bone, a "flap" procedure may be used to replace missing tissue.

Local flap surgery closes the wound left from removing the cancer by rotating or moving nearby skin or tissue. In regional flap surgery, tissue with an attached blood supply is rotated or moved onto the site from a site nearby. This could include muscle and skin from your chest (pectoralis major flap) or skin from your shoulder (supraclavicular flap).

In free flap surgery, also called microvascular reconstruction, a specially trained surgeon removes a "flap" of tissue plus its feeding artery and vein from another part of the body. The surgeon uses this tissue to reconstruct areas in the head and neck, creating a new blood supply by sewing the flap's artery and vein into an artery and vein near the wound. Commonly used areas for free flaps include the forearm, the thigh, the lower leg or the back/shoulder blade.

Gastrostomy tube (G-tube). Some cancers and their treatments can affect the ability to swallow, which may prevent you from getting adequate nutrition. A gastrostomy tube inserted into your stomach through a small incision in your belly acts as a feeding tube, allowing you to receive liquid nutrition (see *Nutrition*, page 18).

Prosthetic rehabilitation. A prosthesis is an artificial replacement for part of your face or mouth (ear, eye, nose, hard palate or teeth). A maxillofacial prosthodontist or anaplastologist will design a custom prosthesis specifically for you.

Tracheostomy. A surgeon creates a hole called a tracheostoma, or stoma, in the front of the neck and connects it to the trachea (windpipe). A hollow plastic tube is inserted to create a new airway to breathe through. This is temporary in most patients during treatment until swelling improves. A tracheostomy tube can easily be removed when it is no longer needed, and the hole will heal.

In surgeries such as a laryngectomy (removal of the voice box), the stoma is permanent and irreversible. A laryngectomy tube (lary tube) is a soft, plastic tube placed during surgery to help in the healing process. Once a patient is healed, no tube has to be worn in the stoma.

FEELING GOOD ABOUT YOURSELF

A healthy self-image can help you move forward with the rest of your life. Ask for referrals to therapists and other specialists. Some of the best advice may come from other head and neck cancer survivors in an online or local support group.

Facial scarring can make you feel insecure. Your external appearance, swelling and scarring will change as you heal and may be further altered by radiation therapy. Some scars will fade over time. Once you heal from treatment, try makeup to help conceal them and even out your skin tone. Some makeup is available with a prescription. Ask your doctor for a recommendation.

You may feel self-conscious if you have difficulties speaking. Speech therapy can help you improve your communication skills and regain confidence. ■

Adjusting to your stoma

As you adapt to your stoma, you may find it helpful to ask for advice from your medical team and other cancer survivors who have them. The following suggestions may also help.

- **Add humidity to the air that is going into your lungs** by using saline squirts and a humidifier when you sleep. Dry air can irritate and cause stoma crusting, coughing and difficulty breathing. Your health care team will explain humidification and a heat and moisture exchange system (HME).
- **Maintaining personal hygiene is important.** When you bathe or shower, use a shower shield, collar, stoma cover or a washcloth to avoid getting water and soap in your stoma. Even the smallest amounts can cause severe coughing and irritation.
- **Daily cleaning is necessary.** Your body may produce more mucus to compensate, which can plug your stoma. Your health care team will provide detailed care instructions. Keep tissues handy throughout the day for extra mucus that is secreted.
- **When you feel the urge to cough, cover your stoma with a tissue** to catch any mucus your cough produces. It may feel strange to cough through your stoma, but most people adjust fairly quickly.
- **Wear comfortable clothes.** Options to disguise your stoma include turtlenecks, scarves, crew neck cotton undershirts and jewelry.
- **If you have dentures, it is important to wear them** while you learn new ways of speaking. Properly fitted dentures will help your mouth compress air to produce speech that is more easily understood, so wear them except when sleeping.
- **Use a stoma cover** to keep pollen, dust, pet hair and aerosol sprays from going directly into your lungs.
- **Wear medical identification** that alerts others you have a stoma.

Learning from others will ease your journey

At HNC Living Foundation, oral cancer survivor Melinda Kurtright helps people who have head and neck cancer find the financial resources they need to live through and beyond their diagnosis. It's a journey she is very familiar with, and she is dedicated to making that path easier for others.

Most everything I'd read about oral cancer wasn't what I actually experienced. Doctors can tell us about the procedures but not exactly what will happen. Everyone's experience is different, so I understand that they don't want to generalize or scare us. That is why stories like this and cancer support groups are so important. Other survivors will tell you their truth.

After living for a year with a tiny sore on my tongue that looked like the tip of a blister, I showed my doctor. I see her quarterly for a back issue, so we began to keep an eye on it. Two and half years after first noticing it, it began to grow and hurt. My doctor sent me to an ENT. As soon as he looked at it, his expression changed.

The official diagnosis was squamous cell carcinoma of the tongue. I had just turned 48. Had I gone to the ENT sooner, my treatment likely would have been surgery only. But, my journey was much different and included a lot of follow-up care.

Treatment began with major surgery from my ear to my throat. The surgeon removed the sore, all the lymph nodes in my neck and 1/8 of my tongue. Radiation therapy followed. I had 45 of the highest doses of radiation offered. It was so much that I'm never allowed to have radiation therapy on my head again.

As I recovered, I had swallow therapy and speech therapy for about a month. It worked — I can speak really well. And unless you examine my tongue, you probably wouldn't notice I'd had such extensive surgery. Just don't ask me to touch my nose with my tongue. I can't do that anymore!

While I recuperated, I lost around 100 pounds. I couldn't get anything down. Fortified drinks were too thick, milkshakes were too cold. My doctor recommended a feeding tube, but I resisted. It really frightened me. In hindsight, it would have made things easier, but at the time I felt like it allowed me to have some control over my body. I finally found something I could get down — room temperature milk from a local dairy. That's what sustained me.

When I first tackled solid food, I had a peanut butter and jelly sandwich, thinking it would be super soft and easy. While I was eating it, my two front bottom teeth snapped off. I had been told that the radiation could cause tooth breakage, but I opted not to have them removed before treatment because even though my teeth weren't beautiful, they were strong and healthy.

I didn't have dental insurance, so I had my dental care at a local university's dental school where they offered it for a low cost. The dental school connected me with a dentist who worked solely with cancer patients. He said my teeth would continue to break off, and he recommended taking them out.

I was 49. There was no way I was ready to lose all my teeth.

It may sound trivial because I know I should have been thankful I was still alive. I was, and still am. But let's face it. I'm human, and I'm a woman. Our physical appearance is tied to our identity. When you have surgery on your mouth, you can't hide it with clothes.

Dentures were very expensive. My wonderful family did what they could to help. My two grown children set up a GoFundMe account. My younger son made chocolate-dipped pretzels and took them to school to sell. Then something happened that changed my life.

My dentist told me about HNC Living, an organization dedicated to helping head and neck cancer patients with the financial burdens of recovery. The dental office applied on my behalf and, through a grant, HNC Living paid for my dentures. I almost jumped up and hugged the dental team when they told me. To call HNC Living angels doesn't even do them justice. They gave me back something I didn't know I was missing — my dignity. When they invited me to work with them soon after, I jumped on it. I wanted to help others the way they helped me.

Even though the cancer may be gone and I feel good physically, it stays on my mind because I found out it runs in my family. My grandfather, who is gone now, had tongue cancer. And a year after my diagnosis, my mom was diagnosed with squamous cell carcinoma of the esophagus. After she had genetic testing, I did, too. She chose to forgo treatment, and she passed away.

Now that we know my kids are at risk, they see the dentist every three months. I follow up with my dentist every six months, and I see my oncologist annually.

I'm afraid cancer of the tongue is not as rare as I want it to be. If something doesn't feel right, advocate for yourself. Doctors are human, too. If they don't see what you're describing, get a second opinion. It could save your life.

Trust in yourself, and trust in God. When you get scared, reach out for help and look for the light at the end of the tunnel. ■

Making a lifelong plan for continued recovery

Recovery from the physical, emotional and mental aspects of head and neck cancer can take more time than you may expect. Be patient as you adjust to this next phase of your life. Moving into survivorship may bring challenges, but it can also offer new opportunities. Be prepared to explain to family, friends, employers and coworkers that you have had a life-altering experience and that some things may have changed.

Set realistic expectations about resuming the routine you had before you were diagnosed with cancer. What was important to you before your cancer diagnosis may no longer be a priority. You may rethink your career path, or you may need modifications at your current job that will allow you to continue being productive. Your employer is required under the Americans with Disabilities Act (ADA) to provide reasonable accommodations. Meet with your human resources representative for details about the ADA and how it applies in your workplace.

You may be surprised to find you feel lonely. Until now, you have been surrounded by many people who continually monitored your care. That support was comforting. Though you won't have as much contact with your medical team, it is important that you continue to have support. Some larger cancer centers and community treatment centers provide survivorship clinics and programs for adults who have had cancer treatment, or you can search online for one. Consider joining a cancer support group or joining the survivor community in another way. There is still more to learn, and sharing your knowledge could offer hope to other survivors.

YOUR SURVIVORSHIP PLAN

Managing your health is easier when you have a plan. Once therapy is finished or as you continue with maintenance therapy, you will work closely with your doctor to develop a survivorship plan.

Following are the common parts of a plan. Yours will be customized for you based on your diagnosis and treatment history, age and other health conditions, and your expectations for the future.

Medical history. This information may include your diagnosis, immunizations, past and current medications, and past and ongoing health conditions. It may also include your family medical history.

Your diagnosis should include the cancer type, subtype and tumor site(s); stage or classification; date of diagnosis; diagnostic test results and pathology reports; and, if applicable, tumor grade, molecular biomarkers present, genetic test results, hormonal status and a summary of second/third opinions.

Part of your medical history will also include a treatment summary that details the following:

- Hospital stays: Reasons, medications, recovery time and complications
- Surgeries: Type, inpatient or outpatient, recovery times and complications
- Radiation therapy: Type, site(s) and total amount of radiation
- Drug therapies: Type, drug names, dosages, duration, side effects and responses
- Supportive care (palliative care): Symptom management, medications (such as for anxiety or nausea), pain management, counseling or other support services for you and/or your loved ones
- Additional services: Physical or occupational therapy, fertility preservation, nutritional counseling, etc.

Follow-up care plan. Before you resume care with your primary care physician, ask your oncologist to set up a long-term follow-up care plan that includes set appointments for regular monitoring. It should also include the following information:

- Follow-up appointment schedule for ongoing monitoring.
- Maintenance medications or therapies, including type, dosage, frequency and duration.
- Referral(s) for cancer rehabilitation, such as physical or occupational therapy, speech therapy, a lymphedema specialist or others.
- Information about your risk of a recurrence, long-term treatment-related side effects and late effects, and a second cancer. Being diagnosed with a head and neck cancer increases your risk for second cancers as well as a recurrence. The risk varies depending on the site of the primary cancer and alcohol and tobacco-related product usage, such as cigarettes, chewing tobacco and electronic cigarettes; the presence of the human papillomavirus (HPV) (see *HPV and Cancer,* page 7); poor dental hygiene; and prolonged exposure to the sun, which is linked to cancer of the lip.
- Note the health care team members you will see for follow-up care, and include their contact information.

Health, wellness and lifestyle recommendations. These may include good nutrition habits, getting to or maintaining a healthy weight, improving fitness and increasing strength. You may have eating challenges from the cancer or its treatment. Working with a dietitian can help ensure you are able to get the nutrients your body needs.

Lifestyle changes such as stopping smoking and managing stress are important to discuss. Ask your primary doctor about getting vaccinations, such as those for COVID-19, shingles or influenza.

Life goals. You may have already shared these goals with your medical team when planning treatment. Now is also a good time to change them or add new ones that better fit in with where you are now.

Survivorship support and community resources. The resources should include your cancer center; survivorship clinics, support groups, cancer advocacy organizations and other local or area resources; survivor phone buddies and peer-to-peer matching; and online survivorship support groups and communities. ■

YOUR SURVIVORSHIP CARE PLAN

Ask your doctor for a plan, or get started on your own. Download a sample Survivorship Care Plan at **PatientResource.com/SurvivorshipPlan.aspx**. Then, request copies of all your test and biopsy results, surgeries, pathology reports and consultation notes from your doctor's office to fill it in.

Embrace your role as a caregiver

Your loved one will rely on you to help in many ways. This role is an incredibly meaningful responsibility that can make a tremendous difference in the life of the person with cancer. Following are some of the most important things you can do to help your loved one manage a head and neck cancer diagnosis.

Educate yourself. Using reputable resources such as this guide and those recommended by the health care team, learn about your loved one's head and neck cancer diagnosis, treatment options and the common challenges ahead.

Manage medications and appointments. Cancer medications are most effective when taken exactly as prescribed. Use a calendar, pill box or reminder tool. Ensure your loved one attends all appointments for treatments and follow ups.

Get permission to receive medical information. Be sure you are authorized to communicate with your loved one's health care team, renew prescriptions and more.

Choose a communication strategy. Your loved one may have challenges communicating, especially after surgery. Before treatment begins, determine how you will communicate with each other, such as writing notes or texting.

Update family and friends. Create an email group so you can send one email to everyone at the same time. This will dramatically reduce phone calls and individual emails as well as ensure that everyone is getting the same information.

Stay alert for side effects. You may notice changes more easily than a doctor or nurse. Before treatment begins, find out which symptoms and side effects require a call to the doctor or emergency medical attention. It helps to track when side effects occur, how long they last and whether anything makes them better. Share this information with the health care team at regularly scheduled appointments or sooner if your loved one is not getting the necessary relief.

Explore rehabilitation options. These may range from surgery and dental implants to physical therapy.

Ask about telehealth. Find out if the medical team offers virtual visits and whether they are covered by insurance. It is convenient for certain types of visits. However, your loved one's health care team may recommend in-person visits early on after treatment so that they can examine them for signs of recurrent cancer or side effects of treatment.

Encourage a healthy lifestyle. This applies to both of you. Follow a nutritious diet, exercise, limit risk of infection and get enough sleep. Ask the dietitian or another member of the team for suggestions.

Surround yourselves with support. Managing a head and neck cancer diagnosis and treatment is difficult for the patient and their loved ones. There are resources to help, such as HNC Living Foundation (hncliving.org) and KEY+YOU (keyplusyou.com). See *Assistance & Support*, page 23, for more resources. ■

Meet the health care team

A multidisciplinary team will be involved in your care.

Anaplastologists specialize in making custom prostheses, such as eyes, ears and noses, to rehabilitate an absent, disfigured or malformed part of the body.

Head and neck oncologic surgeons provide expertise in surgical procedures of the head and neck (an otolaryngologist with specialized surgical training).

Maxillofacial prosthodontists create custom dentures or other prostheses to help restore facial appearance and speech and the ability to eat normally.

Medical oncologists treat cancer with drug therapy or other medications.

Oncologic dentists and **oral oncologists** provide expert dental or oral care for people with head and neck cancer.

Oncology nurses provide inpatient or outpatient care in a cancer treatment facility.

Otolaryngologists treat diseases of the ear, nose and throat; also called an ENT.

Palliative care specialists work to provide physical and emotional relief for cancer symptoms and treatment-related side effects.

Patient navigators and **nurse navigators** serve as guides through diagnosis, treatment and follow-up; may also be patient advocates. They identify barriers to treatment, such as the need for transportation or help with copays and deductibles, and access resources to resolve such barriers. They are also commonly involved with coordination throughout the continuum of care.

Radiation oncologists treat cancer using radiation therapy.

Reconstructive and **plastic surgeons** use reconstructive procedures and techniques to help restore function and appearance after cancer treatment.

Rehabilitation specialists and **physical therapists** help restore movement and build physical strength after cancer treatment.

Registered dietitians and **nutritionists** help meet nutritional challenges that arise during and after treatment by providing nutrition advice based on your medical condition and individual needs.

Social workers assist you and your family if you need psychosocial (emotional) care or assistance, or require resources outside of medical care or advance directive planning.

Speech-language pathologists offer strategies and techniques for regaining or improving the ability to speak, swallow or use other oral motor skills following treatment.

Support and financial resources available for you

BASIC LIVING EXPENSES

Allyson Whitney Foundation ..... www.allysonwhitney.org, 845-707-4681
Bringing Hope Home ..... www.bringinghopehome.org, 484-580-8395
Cleaning for a Reason ..... www.cleaningforareason.org, 877-337-3348
Family Reach Foundation ..... www.familyreach.org, 973-394-1411
HNC Living Foundation ..... www.hncliving.org 913-402-6028
National Cancer Assistance Foundation ..... www.natcaf.org, 866-413-5789
Stupid Cancer ..... www.stupidcancer.org, 212-619-1040

CAREGIVERS & SUPPORT

Cactus Cancer Society ..... www.cactuscancer.org
CanCare ..... www.cancare.org, 888-461-0028
CANCER101 ..... www.cancer101.org, 646-638-2202
Cancer and Careers ..... www.cancerandcareers.org, 646-929-8032
Cancer*Care* ..... www.cancercare.org, 800-813-4673
Cancer Connection ..... www.cancer-connection.org, 413-586-1642
Cancer Hope Network ..... www.cancerhopenetwork.org, 877-467-3638
Cancer Really Sucks! ..... www.cancerreallysucks.org
Cancer Support Community ..... www.cancersupportcommunity.org, 888-793-9355
Cancer Support Community Helpline 888-793-9355
Cancer Survivors Network ..... csn.cancer.org, 800-227-2345
Caregiver Action Network ..... www.caregiveraction.org, 855-227-3640
CaringBridge ..... www.caringbridge.org, 651-789-2300
Center to Advance Palliative Care ..... www.capc.org, 347-835-0658
Chemo Angels ..... www.chemoangels.com
Cleaning for a Reason ..... www.cleaningforareason.org, 877-337-3348
Connect Thru Cancer ..... www.connectthrucancer.org, 484-301-3047
Cooking with Cancer ..... www.cookingwithcancer.org, 205-978-3570
Family Caregiver Alliance ..... www.caregiver.org, 800-445-8106
Friend for Life Cancer Support Network www.friend4life.org, 866-374-3634
The Gathering Place ..... www.touchedbycancer.org, 216-595-9546
Guide Posts of Strength, Inc. ..... www.cancergps.org, 336-883-4483
HPV Cancers Alliance ..... www.hpvalliance.org
Imerman Angels ..... www.imermanangels.org, 866-463-7626
Livestrong Foundation ..... www.livestrong.org, 855-220-7777
Living Hope Cancer Foundation ..... www.getupandlive.org
LivingWell Cancer Resource Center ..... www.livingwellcrc.org, 630-933-7860
Lotsa Helping Hands ..... www.lotsahelpinghands.com
The Lydia Project ..... www.thelydiaproject.org, 877-593-4212
MyLifeLine ..... www.mylifeline.org, 888-793-9355
National HPV Vaccination Roundtable ..... www.hpvroundtable.org
National LGBT Cancer Project ..... www.lgbtcancer.org, 917-301-1913
Patient Empowerment Network ..... www.powerfulpatients.org, 833-213-6657
SHARE Caregiver Circle ..... www.sharecancersupport.org/caregivers-support, 844-275-7427
Stronghold Ministry ..... www.mystronghold.org, 877-230-7674
Triage Cancer ..... www.triagecancer.org, 424-258-4628
Walk With Sally ..... www.walkwithsally.org, 310-322-3900
Well Spouse Association ..... www.wellspouse.org, 732-577-8899
weSPARK Cancer Support Center ..... www.wespark.org, 818-906-3022
Wigs & Wishes ..... www.wigsandwishes.org, 856-582-6600

CHEMOTHERAPY

Chemo Angels ..... www.chemoangels.com
ChemoExperts ..... www.chemoexperts.com
The Chemotherapy Foundation ..... www.chemotherapyfoundation, 212-213-9292

CLINICAL TRIALS

Cancer Support Community ..... www.cancersupportcommunity.org/find-clinical-trial, 888-793-9355
Center for Information & Study on Clinical Research Participation ..... www.searchclinicaltrials.org, 877-633-4376
ClinicalTrials.gov ..... www.clinicaltrials.gov
Head and Neck Cancer Alliance ..... www.headandneck.org/clinical-trials, 866-792-4622
Lazarex Cancer Foundation ..... www.lazarex.org, 877-866-9523, 925-820-4517
National Cancer Institute ..... www.cancer.gov/clinicaltrials, 800-422-6237
NCI Cancer Information Service 800-422-6237
ThyCa: Thyroid Cancer Survivors' Association, Inc. ..... www.thyca.org/about/clinical-trials, 877-588-6078
WCG CenterWatch ..... www.centerwatch.com, 866-219-3440

COMPLEMENTARY PROGRAMS & ALTERNATIVE MEDICINE

Believe Big ..... www.believebig.org
The Center for Mind-Body Medicine ..... www.cmbm.org
National Center for Complementary and Integrative Health ..... www.nccih.nih.gov
Office of Cancer Complementary and Alternative Medicine ..... cam.cancer.gov
Society for Oncology Massage www.s4om.org
Stewart's Caring Place ..... www.stewartscaringplace.org
Touch, Caring and Cancer ..... www.partnersinhealing.net

FERTILITY

Alliance for Fertility Preservation ..... www.allianceforfertilitypreservation.org
American Society for Reproductive Medicine ..... www.reproductivefacts.org, 202-863-4985
Livestrong Foundation ..... www.livestrong.org/what-we-do/program/fertility, 855-220-7777
RESOLVE The National Infertility Association ..... www.resolve.org, 703-556-7172
SaveMyFertility ..... www.savemyfertility.org, 517-884-8848

HEAD & NECK CANCER

Adenoid Cystic Carcinoma Organization International ..... www.accoi.org
Head and Neck Cancer Alliance ..... www.headandneck.org
HNC Living Foundation ..... www.hncliving.org, 913-402-6028
HPV Cancers Alliance ..... www.hpvalliance.org
International Association of Laryngectomees ..... www.theial.com
Light of Life Foundation ..... www.lightoflifefoundation.org
National HPV Vaccination Roundtable ..... www.hpvroundtable.org
Oral Cancer Awareness Foundation (OrCA) www.4orca.org
The Oral Cancer Foundation ..... www.oralcancerfoundation.org
Support for People with Oral and Head and Neck Cancer (SPOHNC) ..... www.spohnc.org
Thyroid Head & Neck Cancer Foundation (THANC) ..... www.thancfoundation.org
ThyCa: Thyroid Cancer Survivors' Association, Inc. ..... www.thyca.org

IMMUNOTHERAPY

Cancer Research Institute ..... www.cancerresearch.org/patients, 800-992-2623
Cancer Support Community ..... www.cancersupportcommunity.org, 888-793-9355
Society for Immunotherapy of Cancer ..... www.sitcancer.org, 414-271-2456

MEDICAL CARE EXPENSES

The Assistance Fund ..... www.tafcares.org, 855-845-3663
Cancer*Care* ..... www.cancercare.org, 800-813-4673
Cancer Warrior, Inc. ..... www.cancerwarriorinc.org, 702-546-8575
Hair to Stay ..... www.hairtostay.org, 800-270-1897
HNC Living Foundation ..... www.hncliving.org, 913-402-6028
Patient Access Network Foundation ..... www.panfoundation.org, 866-316-7263
Patient Advocate Foundation ..... www.patientadvocate.org, 800-532-5274

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline 866-276-7443

NUTRITION

American Cancer Society ..... www.cancer.org, 800-227-2345
Cancer*Care* ..... www.cancercare.org, 800-813-4673
Cancer Support Community ..... www.cancersupportcommunity.org, 888-793-9355
HNC Living Foundation ..... www.hncliving.org
Physicians Committee for Responsible Medicine ..... www.pcrm.org/health-topics/cancer, 202-686-2210
Thyroid Head & Neck Cancer Foundation (THANC) ..... thancfoundation.org/for-patients/eating-healthy-treating-cancer, 646-685-3982

PAIN MANAGEMENT

American Chronic Pain Association ..... www.theacpa.org
American Society of Anesthesiologists ..... www.asahq.org, 847-825-5586
Cancer Pain Research Consortium ..... www.cancerpainresearch.com, 707-260-0849
U.S. Pain Foundation ..... www.uspainfoundation.org, 800-910-2462

PRESCRIPTION EXPENSES

America's Pharmacy ..... www.americaspharmacy.com, 888-495-3181
Cancer*Care* Co-Payment Assistance Foundation ..... www.cancercarecopay.org, 866-552-6729
Cancer Financial Assistance Coalition ..... www.cancerfac.org
Good Days ..... www.mygooddays.org, 972-608-7141
HealthWell Foundation ..... www.healthwellfoundation.org, 800-675-8416
HNC Living Foundation ..... www.hncliving.org, 913-402-6028
Medicine Assistance Tool ..... www.medicineassistancetool.org, 571-350-8643
National Organization for Rare Disorders ..... www.rarediseases.org, 800-999-6673
NeedyMeds ..... www.needymeds.org, 800-503-6897
Patient Access Network Foundation ..... www.panfoundation.org, 866-316-7263
Patient Advocate Foundation Co-Pay Relief ..... www.copays.org, 866-512-3861
RxAssist ..... www.rxassist.org
RxHope ..... www.rxhope.org
SingleCare ..... www.singlecare.com, 844-234-3057
Stupid Cancer ..... www.stupidcancer.org, 212-619-1040
Together Rx Access ..... www.togetherrxaccess.com, 800-444-4106

RADIATION ONCOLOGY

American Society for Radiation Oncology ..... www.astro.org, 703-502-1550
National Association for Proton Therapy ..... www.proton-therapy.org, 202-919-4536
RadiologyInfo.org ..... www.radiologyinfo.org
RT Answers ..... www.rtanswers.org, 703-502-1550
Society of Interventional Radiology ..... www.sirweb.org, 703-691-1805

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Bayer US Patient Assistance Foundation ..... patientassistance.bayer.us, 866-228-7723
Bristol-Myers Squibb Access Support ..... bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation ..... bmspaf.org, 800-736-0003
Cabometyx EASE ..... www.cabometyx.com/financial-support, 844-901-3273
Caprelsa Access Support ..... caprelsa.com/pt_resources_and_support.asp, 800-367-4999
Cometriq EASE ..... cometriq.com/support, 844-900-3273
Erbitux Savings Card ..... www.lillyoncologysupport.com/erbitux-financial-support, 866-472-8663
Gavreto Financial Assistance ..... www.gavreto.com/thyroidcancer.html#financial-assistance, 888-258-7768
Genentech Access Solutions ..... genentech-access.com/patient, 877-436-3683
Genentech Oncology Co-pay Assistance Program ..... copayassistancenow.com/patients, 855-692-6729
Genentech Patient Foundation ..... www.gene.com/patients/patient-foundation/apply-for-help#patients, 888-941-3331
Keytruda KEY+YOU ..... www.keyplusyou.com, 855-398-7832
Keytruda Merck Access Program ..... www.merckaccessprogram-keytruda.com/hcc/, 855-257-3932
Lenvima Eisai Reimbursement Resources ..... eisaireimbursement.com/patient/lenvima, 866-613-4724
Lilly Cares Foundation Patient Assistance Program ..... www.lillycares.com, 800-545-6962
Lilly Oncology Support Center ..... www.lillyoncologysupport.com, 866-472-8663
Merck Access Program ..... merckaccessprogram.com/hcc/
Merck Patient Assistance Program ..... merckhelps.com, 800-727-5400
Nexavar $0 Co-Pay Program ..... www.zerocopaysupport.com/nexavar, 866-581-4992
Nexavar Access Services by Bayer ..... www.nexavar-us.com/access-services-by-bayer, 800-288-8374
Novartis Oncology Universal Co-pay Program ..... copay.novartisoncology.com, 877-577-7756
Novartis Patient Assistance Foundation ..... www.novartis.us/our-products/patient-assistance/patient-assistance-foundation-enrollment, 800-277-2254
Novartis Patient Assistance NOW Oncology (PANO) ..... patient.novartisoncology.com/financial-assistance/pano, 800-282-7630
Opdivo BMS Access Support ..... patientsupport.bmscustomerconnect.com/opdivo-with-you-registration, 855-673-4861
Retevmo Savings Card ..... www.retevmo.com/savings-support, 866-472-8663
Rozlytrek Access Solutions ..... www.genentech-access.com/patient/brands/rozlytrek, 877-436-3683
Sanofi Patient Connection ..... sanofipatientconnection.com, 888-847-4877
Tafinlar + Mekinist Financial Resources ..... www.us.tafinlarmekinist.com, 877-577-7756
Vitrakvi Access Services by Bayer ..... www.vitrakvi-us.com/patient-assistance-program, 800-288-8374

STOPPING TOBACCO USE

American Cancer Society ..... www.cancer.org
BecomeAnEx ..... www.becomeanex.org
National Cancer Institute Smoking Quitline 877-448-7848
North American Quitline Consortium ..... naquitline.org, 800-398-5489
QuitSTART ..... teen.smokefree.gov
Smokefree.gov ..... smokefree.gov
SmokefreeTXT ..... smokefree.gov/smokefreetxt
Tobacco Quitline 1-800-QUIT-NOW (800-784-8669)

SURVIVORSHIP

13thirty Cancer Connect www.13thirty.org
A Time to Heal Cancer Foundation ..... www.atimetohealfoundation.org, 402-401-6083
American Society of Clinical Oncology ..... www.cancer.net/survivorship, 888-651-3038
Angel On My Shoulder ..... angelonmyshoulder.org
Cactus Cancer Society ..... www.cactuscancer.org
Cancer ABCs ..... www.cancerabcs.org, 516-445-2026
Cancer and Careers ..... www.cancerandcareers.org, 646-929-8032
Cancer*Care* ..... www.cancercare.org
Cancer Hope Network ..... www.cancerhopenetwork.org, 877-467-3638
Cancer Support Community ..... www.cancersupportcommunity.org, 888-793-9355
Cancer Survivors Network ..... csn.cancer.org, 800-227-2345
Catherine Boulay Foundation ..... catherineboulayfoundation.org, 610-966-3466
Centers for Disease Control and Prevention (CDC) ..... www.cdc.gov/cancer/survivors, 800-232-4636
Global Resource for Advancing Cancer Education (GRACE) ..... www.cancergrace.org
Hope for Two... The Pregnant with Cancer Network ..... www.hopefortwo.org
Imerman Angels ..... www.imermanangels.org, 866-463-7626
Indian American Cancer Network ..... www.iacannetwork.org
Law Enforcement Cancer Support Foundation ..... www.lawenforcementcancer.org
Livestrong Foundation ..... www.livestrong.org
National Cancer Survivors Day ..... ncsd.org, 615-794-3006
National Coalition for Cancer Survivorship ..... www.canceradvocacy.org, 877-622-7937
National LGBT Cancer Network ..... www.cancer-network.org, 212-675-2633
National LGBT Cancer Project ..... www.lgbtcancer.org, 917-301-1913
Reel Recovery ..... www.reelrecovery.org, 208-303-0040
River Discovery ..... riverdiscovery.org
Stupid Cancer ..... www.stupidcancer.org, 212-619-1040
Survivor's Outdoor Experience ..... www.survivorsoutdoorexperience.org
Triage Cancer ..... www.triagecancer.org, 424-258-4628
True North Treks ..... truenorthtreks.org
Walk With Sally ..... www.walkwithsally.org, 310-322-3900

VETERANS' ASSISTANCE

Cancer*Care* ..... www.cancercare.org, 800-813-4673
Family Caregiver Alliance ..... www.caregiver.org, 800-445-8106
Fisher House Foundation ..... www.fisherhouse.org, 888-294-8560
National Hospice and Palliative Care Organization ..... www.nhpco.org, 703-837-1500
U.S. Pain Foundation ..... www.uspainfoundation.org, 800-910-2462

➡ ***For more resources, go to*** PatientResource.com

HNC Living FOUNDATION

HNC Living Foundation was formed specifically to help head and neck cancer patients live life fully during and after treatment by providing financial aid. Our grants fund services and programs that directly benefit head and neck cancer patients, supporting their treatment and recovery.

CONTACT US

- **Phone:** 913.402.6028
- **Email:** information@hncliving.org
- **Website:** hncliving.org/for-patients/

WHAT WE HELP WITH

We provide assistance to help with costs incurred as a direct result of head and neck cancer treatment and recovery that aren't covered by insurance. Sample costs include the following:

- **Co-pays & Deductibles**
  (for appointments & treatments)
- **Dental Care**
  including pre-radiation dental clearance, dentures, and other dental treatment resulting from head and neck cancer
- **Nutritional Supplements**
- **Medical Supplies & Equipment**
  (not covered by insurance)
- **Medication & Prescriptions**
  (not covered by insurance)
- **Gas Cards** *(to appointments & treatments)*

We are not able to provide assistance with rent or mortgages, utilities, home modifications, groceries, or with medical bills acquired before the application date.

Susan, an HNC Living Foundation patient

WHO WE HELP

HNC Living Foundation provides people struggling with the financial hardships of cancer. Our funding aims to help those who are at or below 250% of the federal poverty guideline. We assist patients diagnosed with the following types of head and neck cancer:

- **Salivary Gland**
- **Throat or Pharynx**
- **Upper Esophageal**
- **Nasal & Sinus**
- **Thyroid**
- **Laryngeal**
- **Oral**

PATIENT
RESOURCE

Where information equals hope