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2020

Oropharyngeal Cancer

HEAD AND NECK CANCERS SERIES

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These NCCN Guidelines for Patients® are based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Head and Neck Cancers (Version 1.2020, February 12, 2020).

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Head and Neck Cancer Alliance

As an organization that works to advance prevention, detection, treatment and rehabilitation of oral, head and neck cancers, the Head and Neck Cancer Alliance strongly supports and endorses these NCCN Guidelines for Patients. headandneck.org



Oral Cancer Foundation

The foundation is pleased to support and endorse the NCCN Guidelines for Patients. These guidelines provide another tool for patients to make sound science-based decisions from as they navigate the treatment options and journey through the cancer experience. As an organization that works to provide vetted information to patients and caregivers, sponsor research, advocate for issues that impact this patient population, and provide real time support for them from both an emotional support and science based treatment perspective, we understand that sound factual knowledge is empowering. It ultimately is a key component of decision making that yields better long-term outcomes. We appreciate having another powerful tool in the armamentarium available to them. oralcancerfoundation.org



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SPOHNC is honored to support and endorse the new NCCN Guidelines for Patients. Together we can help to raise awareness, educate and support patients with the necessary tools that will guide them while choosing their treatment options and managing their care. Together we are committed to offering oral, head and neck cancer patients and their loved ones the best support services available to live a better quality of life from diagnosis through recovery. spohnc.org

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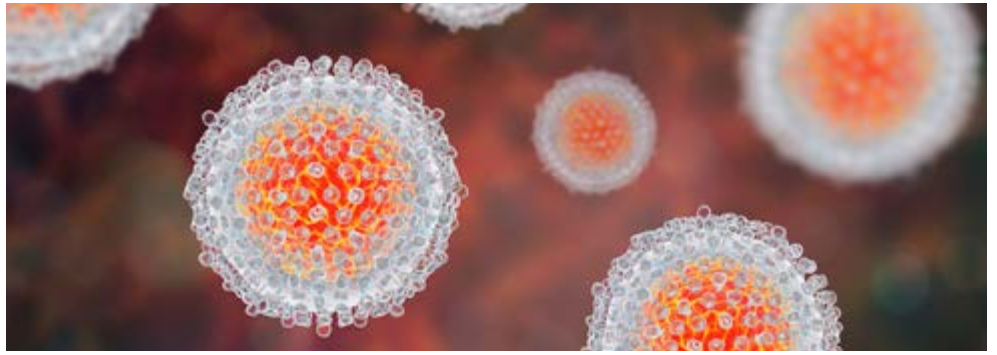
THANC – The THANC Foundation is pleased to endorse this valuable resource. We believe this comprehensive guide will help patients understand and prepare for every step of the head and neck cancer journey. thancfoundation.org

Thyroid Care Collaborative – The Thyroid Care Collaborative strongly endorses this valuable resource. We believe this comprehensive guide will ensure patients are well-informed - an important step to the fight against head and neck cancer! thyroidccc.org

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WHAT
SHOULD
I DO



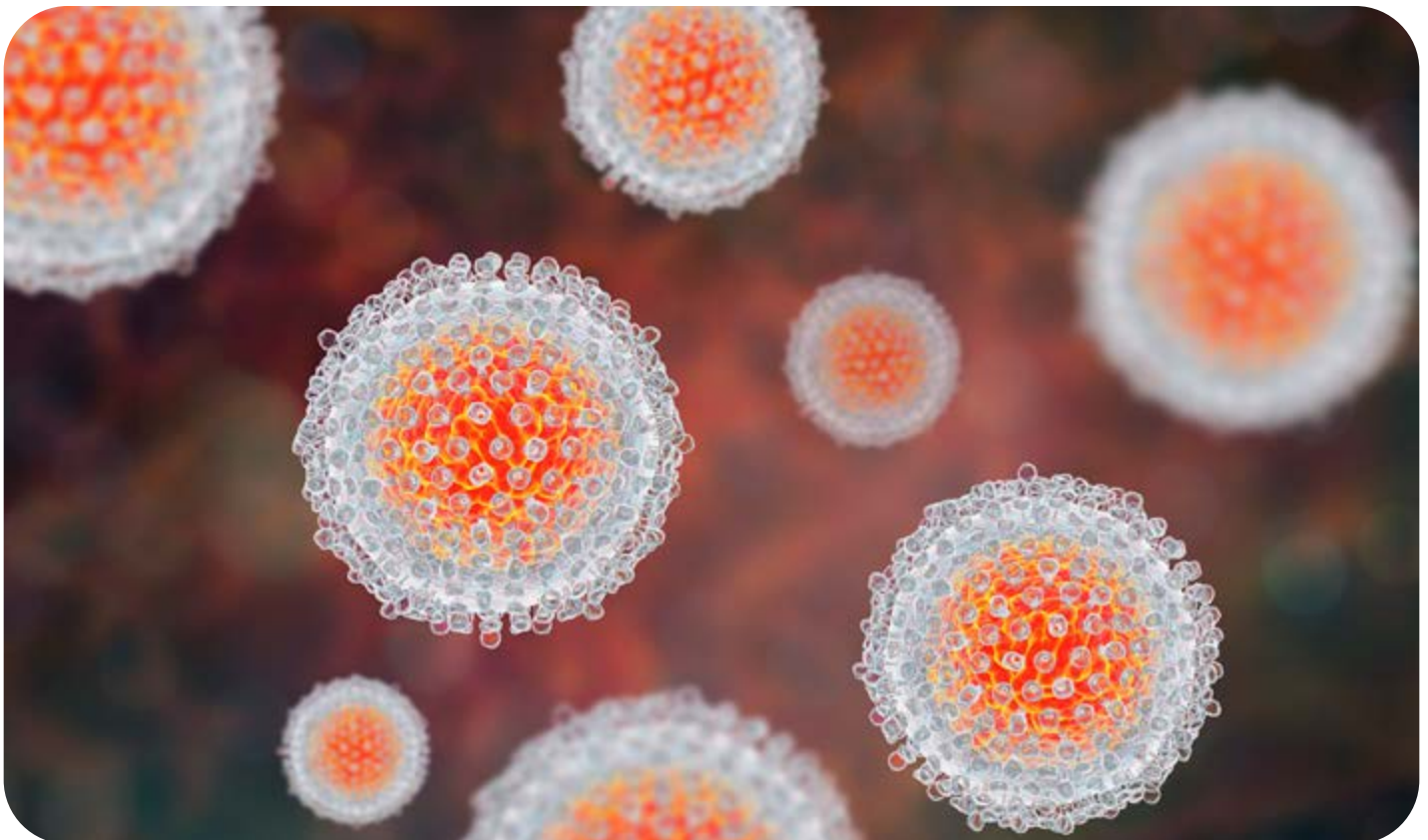
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1

Oropharyngeal cancer basics

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Oropharyngeal cancer is a type of throat cancer. Read this chapter to learn where this cancer grows and what puts people at risk for this cancer.

The throat

Before learning about oropharyngeal cancer, it is helpful to know about the throat. The throat is also called the pharynx.

Pharynx

The pharynx is a tube-like structure within the head. It starts behind the nose and ends at the voice box (larynx). Food passes from the mouth through the pharynx on its way to the stomach. Air also passes from either the mouth or nose through the pharynx on its way to the lungs.

The pharynx has 3 parts, which are the:

- nasopharynx,
- oropharynx, and
- hypopharynx.

The nasopharynx is behind the nose. The oropharynx is below the nasopharynx. The hypopharynx is below the oropharynx and just behind the voice box.

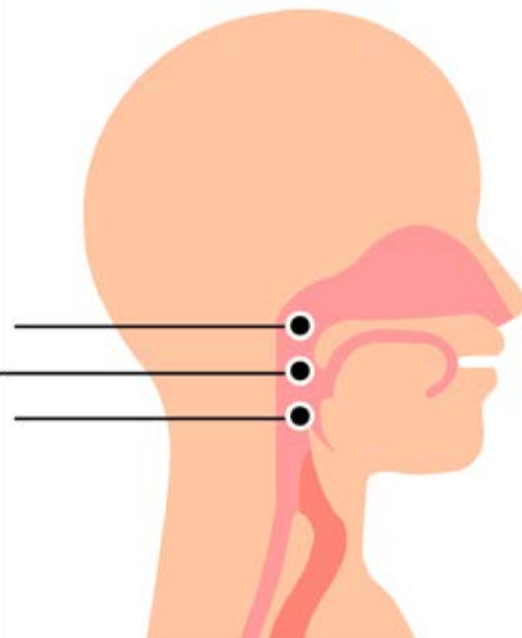
Lymph nodes

Throughout your body—including your throat—is a clear fluid called lymph. Lymph contains germ-fighting blood cells. Fluid from between cells drains into lymph. Lymph travels through channels that transport it to the bloodstream.

The throat

The throat is also called the pharynx. It has three parts. Behind the nose is the nasopharynx. Below the nasopharynx is the oropharynx and then the hypopharynx.

Nasopharynx
Oropharynx
Hypopharynx



As lymph travels, it passes through lymph tissue. Lymph tissue removes germs from lymph. Lymph nodes are small structures that contain lymph tissue. They are found throughout the body. There are many lymph nodes in the neck.

The tonsils are larger clusters of lymph tissue. There is a tonsil on the left and right side of the throat. There are similar clusters of lymph tissue in the nasopharynx and at the back of the tongue.



Above all, never give up. Give luck a chance to happen by doing all within your control to survive.”

– Mary

Tongue cancer survivor

Lymph nodes

Throughout your body is a clear fluid called lymph. Lymph travels through vessels to the bloodstream. As lymph travels, it passes through small structures called lymph nodes. Lymph nodes remove germs from lymph. Lymph vessels and nodes are depicted in green in the figure.



Head and neck cancer

Head and neck cancer is a group of cancers. It includes cancers of the inner lip, mouth, throat, voice box, nose, and sinuses. These cancers are referred to as upper aerodigestive tract cancers.

Oropharyngeal carcinoma

This book is about treatment for oropharyngeal carcinoma. Almost all cancers of the oropharynx are squamous cell carcinomas. Carcinomas are cancers of cells that line the inner or outer surfaces of the body.

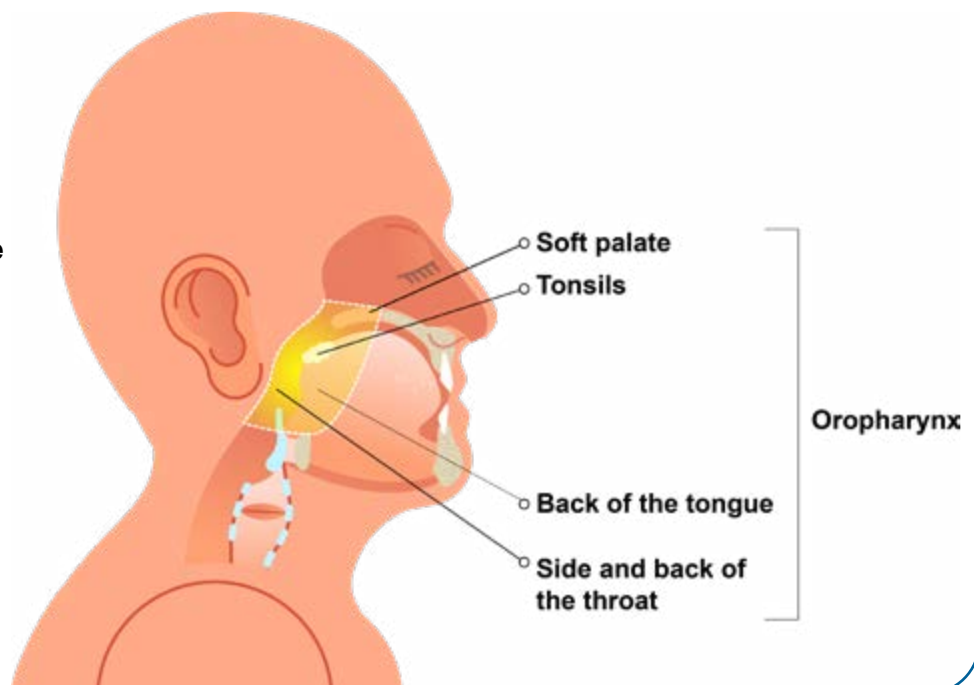
Oropharyngeal carcinoma forms from cells that line the oropharynx. The parts of the oropharynx are:

- base of the tongue,
- tonsils,
- soft palate, and
- walls of the middle part of the throat.

The cancer cells can form into a tumor within the oropharynx. This is called the primary tumor. This tumor can grow into nearby tissue, such as the voice box and tongue muscle. Cancer cells from oropharynx often spread to lymph nodes in the neck.

The oropharynx

The oropharynx is the middle part of the throat. The parts of the oropharynx are the base of the tongue, tonsils, soft palate, and the walls of the middle throat.



Risk factors

A risk factor is anything that increases your chance of cancer. Risk factors linked to oropharyngeal cancer are:

- Tobacco use
- Infection with human papillomavirus (HPV)

Oropharyngeal cancers that are related to HPV differ from cancers unrelated to HPV. People with HPV-related cancer tend to be younger. The outlook (prognosis) of HPV-related cancer is better. More research is needed to learn what treatments work best for each type of oropharyngeal cancer.

To take differences into account, oropharyngeal cancer is often grouped by HPV status. Cancers not related to HPV are called HPV negative. Cancers related to HPV are called HPV positive.

Treatment types

This section briefly describes treatments for oropharyngeal cancer. Not everyone receives the same treatment. Your doctors will tailor treatment to you based on tests described in **Part 2**.

In this book, options for initial treatment are grouped by HPV status. Options for HPV-negative cancer are listed in **Part 3**. Options for HPV-positive cancer are listed in **Part 4**. Treatment for cancer that persists or returns after initial treatment is discussed in **Part 6**.

Clinical trial

One treatment choice may be a clinical trial. Clinical trials are strongly supported by NCCN. NCCN believes that you will receive the best management if treated in a clinical trial.

A clinical trial is a type of research that studies a promising test or treatment in people. It gives people access to health care that otherwise couldn't usually be received. Clinical trials often include new treatments that are added to standard treatments. Ask your treatment team if there is an open clinical trial that you can join.

Surgery

Surgery is a treatment that removes tumors or entire organs with cancer. It is a very common treatment for oropharyngeal cancers. The primary tumor, lymph nodes, or both may be removed during surgery.

The method to remove the cancer depends on where and how much the cancer has grown. The cancer may have grown near or around blood vessels and nerves. Most often, surgeons remove oropharyngeal cancers through an open mouth.

The cutting device that is used may be a surgical knife, heated device, or laser beam. A machine ("robot") may be used to remove the cancer. Surgeries with lasers or a robot should only be performed by a surgeon with the proper training and experience.

Radiation therapy

Radiation therapy uses high-energy x-rays or particles to treat oropharyngeal cancer. It damages cancer cells. The cancer cells either die or stop making new cancer cells.

External beam radiation therapy (EBRT) is used for treatment. A large machine makes radiation beams that are shaped to the form of the tumor. The highest radiation dose is aimed at the cancer. A much lower dose is given to nearby tissue. NCCN experts recommend the following techniques:

- Intensity-modulated radiation therapy (IMRT) is a commonly used technique. It delivers x-ray beams that very closely match the shape of the target and spare more normal tissue.
- Proton therapy treats cancer with proton beams. Proton beams deliver radiation mostly within the tumor. NCCN experts advise to get proton therapy only when x-ray beams would damage too much normal tissue.

A radiation oncologist is a doctor who is an expert in treating cancer with radiation. Radiation therapy to the head and neck should only be done by a radiation oncologist with the proper training and experience.

Chemotherapy

Chemotherapy is a treatment with drugs that stop the cell life cycle. As a result, cancer cells cannot make new cells. Chemotherapy can also cause cells to destroy themselves.

Cisplatin, carboplatin, 5-fluorouracil (5-FU), and docetaxel are commonly used to treat oropharyngeal cancer. There are other drugs that are less often used but can work.

Targeted therapy

Targeted therapy is a treatment with drugs that stop some of the ways by which cancer cells grow. Cetuximab is a targeted therapy that

stops growth signals from a structure called EGFR that is on cancer cells. It also allows immune cells to destroy the cancer cells.

Immunotherapy

T cells are a type of white blood cell. They help fight disease, including cancer. But, they are unable to attack cancer cells that have a protein called PD-L1.

Immune checkpoint inhibitors are a type of immunotherapy. These drugs include pembrolizumab and nivolumab. They allow T cells to attack cancer cells with PD-L1.

Review

- The oropharynx is the middle part of the throat that is behind the mouth.
- Most oropharyngeal cancers form from cells that line the surface of the tongue base, tonsils, soft palate, and walls of the middle throat.
- Tobacco use and infection with HPV can increase the chance of getting oropharyngeal cancer.
- Not everyone with oropharyngeal cancer receives the same treatment. Your doctors will tailor treatment to you.

2

Testing for oropharyngeal cancer

13 General health tests

14 Distress screening

15 Imaging

16 Endoscopic exam

17 Biopsy

17 HPV test

18 Preanesthesia exam

18 Other tests

19 Smoking treatment

19 Fertility counseling

20 Review



Valid tests are needed to identify oropharyngeal cancer and plan treatment. This chapter describes tests and other health care that you may receive before cancer treatment.

Cancer doctors plan treatment using many sources of information. One of these sources is you. Tell your doctors your concerns and goals for treatment. Together, you can share in the decision-making process. Tests and other health care that you may receive are listed in [Guide 1](#).

General health tests

Medical history

Your doctors will want to know about any health problems and their treatment during your lifetime. Be prepared to talk about:

- Illnesses
- Injuries
- Health conditions
- Symptoms
- Medications
- Tobacco use (now and in the past)

Family history

Some cancers and other health problems can run in families. Thus, your doctors will ask about the medical history of your close blood relatives. Such family includes your siblings, parents, and grandparents. Be prepared to tell who has had what diseases and at what ages.

Guide 1

Health care before cancer treatment

Medical history

Physical exam including head and neck exam

Distress screening

CT with contrast, MRI with contrast, or both of the oropharynx and neck

FDG PET/CT if needed

Chest CT, if needed, with or without contrast

Endoscopy if needed

Biopsy

HPV test on cancer tissue

Preanesthesia exam if needed

Dental exam with Panorex if needed

Speech and swallowing exam if needed

Nutrition assessment if needed

Hearing test if needed

Smoking treatment if needed

Fertility counseling if needed

Medications

It may help to bring a list of your old and new medicines to the doctor's office.

Physical exam

A physical exam is a study of your body. It is done to look for signs of disease. It is also used to help assess what treatments may be options.

During this exam, expect the following to be checked:

- Your body temperature
- Your blood pressure
- Your pulse and breathing rate
- Your weight
- How your lungs, heart, and gut sound
- How your eyes, skin, nose, ears, and mouth look
- The size or hardness of your organs
- Level of pain when you are touched

Head and neck exam

An exam of your head and neck is key to planning treatment. Your doctors will carefully inspect your throat, mouth, nose, and ears. Your doctors will feel for lumps under your jaw and along your neck.

To look inside your head, your doctors may use a device. One type of device is a small mirror like what your dentist uses to look inside your mouth. Your doctors may also examine your throat with a fiberoptic endoscope.

Distress screening

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect how you feel, think, and act. It can include feelings of:

- Sadness
- Fear
- Helplessness
- Worry
- Anger
- Guilt

Everyone with cancer has some distress at some point in time. It is to be expected.

Feeling distressed may be a minor problem or it may be more serious. You may be so distressed that you can't do the things you used to do. People with head and neck cancer are at risk for depression.

It is important that your treatment team knows how you feel. They may ask you to complete a list of screening questions to assess how distressed you are.

If needed, your treatment team can get you help. Help can include support groups, talk therapy, or medication. Some people also feel better by exercising, talking with loved ones, or using relaxation techniques. There may also be helpful community resources, such as support groups and wellness centers.

FDG PET/CT

Sometimes CT is combined with positron emission tomography (PET). When used together, they are called a PET/CT scan. PET requires injecting a radiotracer into your bloodstream. It can show even small amounts of cancer.

Your doctors may want you to get PET/CT with a fluorodeoxyglucose (FDG) radiotracer. It is used to help define the primary tumor. It is also used to look for cancer in lymph nodes or distant body parts. It may show cancer that was not seen with other imaging.

Chest CT

A chest CT is used to look for tumors in the chest. You may get this scan if the cancer has spread to lymph nodes. Or, this scan may be done if you have a high risk for lung cancer. Contrast may or may not be used.

Endoscopic exam

Some people will get an endoscopic exam. An endoscope is a hand-held device used to see inside your body. Your doctor will guide its thin, tube-shaped part through your nose or mouth. At the tip of the scope is a light and tiny camera. With the scope, your doctor will assess the extent of the tumor.

CT machine

Pictures of the insides of your body can be made with imaging. During the scan, you will lie on a table that will move into the tunnel of the machine. The pictures will be viewed by a doctor who will look for signs of cancer.



Biopsy

A biopsy is a procedure that removes tissue or fluid samples for testing. Doctors decide where to do a biopsy based on the physical exam and imaging. In a lab, a pathologist will study the samples with a microscope. The lab tests will conclude whether you have cancer.

There are different types of biopsies.

- Your doctor may use a scissor-like tool to remove part or all of the tumor.
- Your entire tonsil may be removed for testing during a surgery called a tonsillectomy.
- A fine-needle aspiration (FNA) removes a small number of cells and is preferred for a neck lump.

All biopsy results are included in a pathology report. This report will be sent to your doctors. Ask for a copy and a meeting to discuss the results. Take notes and ask questions.

HPV test

Not everyone with HPV gets oropharyngeal cancer. But, there is a very strong link between the virus and the cancer. Everyone with oropharyngeal cancer should have a sample of the tumor tested for HPV. A sample obtained through FNA may be sufficient.

There is more than one lab test for HPV. NCCN experts recommend p16 immunohistochemistry (IHC). Polymerase chain reaction (PCR) and in situ hybridization (ISH) are other lab tests that may be used.



Team work

It takes a team of health care providers to treat oropharyngeal cancer. Your treatment team may include a:

- ✓ Radiation oncologist
- ✓ Medical oncologist
- ✓ Head and neck surgeon
- ✓ Nurse
- ✓ Pathologist
- ✓ Radiologist
- ✓ Oncologic dentist
- ✓ Eye doctor
- ✓ Ear doctor
- ✓ Plastic surgeon
- ✓ Speech-language pathologist
- ✓ Physical therapist
- ✓ Registered dietician
- ✓ Case manager
- ✓ Mental health professional
- ✓ Supportive care specialist

Preanesthesia exam

Anesthetics are medicines that prevent pain during a procedure or surgery. For major surgery, general anesthesia is used. It will put you in a sleep-like state. An anesthesiologist is a doctor who gives anesthesia.

The anesthesiologist will assess if general anesthesia is safe for you. This doctor may review your medical records, ask you questions, and do a physical exam. Sometimes, tests are ordered.

Other tests

There are many key body parts in the head and neck. Oropharyngeal cancer or its treatment can cause problems with one or more of them. Based on your symptoms and cancer tests, you may get one or more of these tests:

- Dental exam
- Speech and swallowing exam
- Nutrition assessment
- Hearing test

Dental exam

If needed, a dental exam can help your cancer doctor plan treatment. It may also prevent health problems caused by treatment. When fewer problems occur, cancer treatments may work better. Ask your cancer center for a list of local dentists who can help.

During a dental exam, the dentist will inspect your mouth and teeth. X-rays of your teeth may also be done. Cavities will be fixed. Unhealthy teeth will be removed to prevent problems

during or after treatment. Diseases of the mouth will also be treated.

Your dentist will teach you how to take care of your teeth. Proper brushing, flossing, and diet are needed. Before cancer treatment, custom-made trays for fluoride treatment may be made.

Cancer treatments may cause dental problems. Your dentist will teach you about these health problems. You will also learn how to prevent or stop such problems.

Panorex x-ray

A Panorex x-ray shows more than just your teeth. It is an x-ray of the entire mouth. It can show if the cancer has grown into your jaw. You may get this test in addition to routine x-rays if needed.

Speech and swallowing exam

Throat cancer or its treatment can cause problems with speech or swallowing. If you have or will have problems, you should see a speech-language pathologist. Before cancer treatment, this expert will assess how well you speak and swallow.

The speech-language pathologist will watch and listen as you talk and eat. You may also get a swallow test called a video fluoroscopic study. You will be given a therapy plan to reduce problems.

Nutrition assessment

Some throat cancers make it hard to eat. It may be painful to chew or swallow. In this case, you may see a registered dietician before cancer treatment. Be prepared to report what you eat and drink. Based on your response, the dietician will make a nutritional plan for you.

You may be assessed for a feeding tube. A feeding tube may be helpful now if you have swallowing problems and are losing weight. Swallowing problems may get worse during cancer treatment and a feeding tube may be needed in time.

There are different types of feeding tubes. A nasogastric tube is placed through the nose, down the throat, and into the stomach. A percutaneous endoscopic gastrostomy (PEG) tube is placed through the skin directly into the stomach.

Hearing test

Oropharyngeal cancer or its treatment may affect the ears. The cancer can grow and press on part of the inner ear called the eustachian tube. Cancer symptoms include frequent ear infections, hearing loss, ear pain, and ringing in the ear. If needed, your cancer doctor may refer you to get a hearing test.

Smoking treatment

If you smoke or chew tobacco, it is important to quit. Both are causes of many types of cancers, including head and neck cancers. They can also limit how well cancer treatment works.

Nicotine addiction is one of the hardest addictions to stop. The stress of having cancer may make it harder to quit. There is help. Ask your doctors about counseling and medications to help you quit.

Fertility counseling

Some cancer treatments can damage body parts that are needed to have a baby. Not being able to have a baby is called infertility. It can happen to people of any gender. Ask your cancer doctor if you are at risk for infertility.

You may want to have children after cancer treatment or are unsure. You can receive a referral to a fertility specialist. A fertility specialist is an expert in helping men and women have babies. The fertility specialist can explain how you may be able to have a baby after treatment.



When you are diagnosed with cancer, go to a cancer hospital! After that, go to another cancer hospital for a second opinion. This can literally mean the difference between life and death, or the quality of your life post treatment.”

– Paul
HPV-related tonsil cancer survivor

Review

- A medical history is a report of all health events and treatment in your lifetime. Expect to be asked questions about your health and the health of some family members.
- A physical exam is a study of your body. During a head and neck exam, your doctor will carefully inspect your throat, mouth, nose, and ears.
- People with head and neck cancer are at risk for depression. Your treatment team can get you help.
- Imaging allows your doctors to see inside your body without cutting into it. It is used to assess what body parts may have cancer.
- A biopsy removes a small piece of tissue for testing. It is needed to learn if you have cancer.
- Your doctor may examine your throat by inserting part of a scope through your nose or mouth.
- A sample of tumor should be tested for HPV.
- Oropharyngeal cancer and its treatment may cause problems with key body parts in your head and neck. Your cancer doctor may refer you for tests given by other specialists.
- If you smoke, your treatment team can get you help to quit.
- Talk to a fertility specialist if you want to have a baby after cancer treatment and are at risk for infertility.



Caregivers need to understand this disease. Treatment is every bit as difficult on them as it is on their loved one.”

– Linda

Head-and-neck cancer survivor

3

HPV-negative cancer

- 22 Overview
- 24 Cancer stage
- 26 Primary treatment
- 30 Adjuvant treatment
- 33 Review



This chapter is about initial treatment for HPV-negative oropharyngeal cancer. Treatment options are based on the cancer stage and other factors. Discuss with your doctors which options in this chapter are right for you.

Overview

Oropharyngeal cancers that are unrelated to human papillomavirus (HPV) are a different disease than cancers related to HPV.

Oropharyngeal cancer that is not related to HPV is called HPV negative. This chapter is about the first treatments for HPV-negative oropharyngeal cancer.

Treatment for oropharyngeal cancer includes treatment for the cancer and support for you. Many HPV-negative oropharyngeal cancers are cured. If a cure is not possible, the goals of treatment are to reduce symptoms, control cancer growth, and extend life. During and after cancer treatment, you may meet with health providers whose focus is to improve your quality of life.

Multidisciplinary team

A multidisciplinary team consists of experts from different fields of medicine. Examples of experts include a head-and-neck surgeon, radiation oncologist, and medical oncologist. It is important that your information be reviewed by a multidisciplinary team.

You are part of the team. The experts should explain their preferred treatment plan to you. Ask about the pros and cons of the plan. Ask

about any other treatment options. Tell your team your goals and wishes for treatment.

Cancer stage

Your doctors will plan your initial treatment based on many factors. These factors include your age and level of fitness. Treatment will also be based on the cancer. A very important factor is the cancer stage. The stages of HPV-negative oropharyngeal cancer are explained in the next section.

Primary treatment

Primary treatment is the main treatment of cancer. It may consist of local treatment, systemic treatment, or both.

- A local treatment targets cancer in a confined area. It includes radiation therapy and surgery.
- Systemic treatment treats cancer throughout the body. It includes chemotherapy, targeted therapy, and immunotherapy.

A common treatment for oropharyngeal cancer is radiation therapy with systemic therapy. Both treatments are given during the same time period. This combined treatment is sometimes called “concurrent radiation therapy and systemic therapy.”

Adjuvant treatment

Adjuvant treatment helps stop a cancer from coming back. It is sometimes given after surgery or radiation therapy. The end of this chapter will explain who will likely need adjuvant treatment and which treatments are options.

IN DEPTH

Systemic therapy regimens

Systemic therapy used
with other treatment:

Regimens used with radiation therapy for primary treatment

Preferred

- High-dose cisplatin
- Carboplatin, infusional 5-FU

Other

- 5-FU, hydroxyurea
- Carboplatin, paclitaxel
- Cetuximab
- Cisplatin, infusional 5-FU
- Cisplatin, paclitaxel
- Weekly cisplatin

Regimens used with radiation therapy for adjuvant treatment

Preferred

- Cisplatin

Other

- None

Induction regimens

Preferred

- Docetaxel, cisplatin, 5-FU

Other

- Paclitaxel, cisplatin, infusional 5-FU

Regimens used with radiation therapy after induction

Preferred

- Weekly carboplatin
- Weekly cisplatin

Other

- Weekly cetuximab

Systemic therapy
used alone:

First-line regimens

Preferred

- Cetuximab, (cisplatin or carboplatin), 5-FU
- Pembrolizumab, (cisplatin or carboplatin), 5-FU
- Pembrolizumab for cancers with PD-L1 marker

Other

- Cisplatin, cetuximab
- (Cisplatin or carboplatin), docetaxel
- (Cisplatin or carboplatin), paclitaxel
- Cisplatin, 5-FU
- (Cisplatin or carboplatin), docetaxel, cetuximab
- (Cisplatin or carboplatin), paclitaxel, cetuximab
- Cisplatin
- Carboplatin
- Paclitaxel
- Docetaxel
- 5-FU
- Methotrexate
- Cetuximab
- Gemcitabine
- Capecitabine

Second-line regimens

Preferred

- Nivolumab if platinum therapy failed
- Pembrolizumab if platinum therapy failed

Other

- Cisplatin, cetuximab
- Cisplatin, (docetaxel or paclitaxel)
- Carboplatin, (docetaxel or paclitaxel)

Cancer stage

The cancer stage is a rating of the extent of cancer in the body. Your doctors use it for many things. It is used to assess the outlook of the cancer (prognosis). It is used to plan treatment. It is also used for research.

The American Joint Committee on Cancer (AJCC) staging system is used to stage oropharyngeal cancer. In this system, the letters T, N, and M describe the extent of the cancer.

T score

The T score describes the growth of the primary tumor. The primary tumor is a mass of cancer cells in the oropharynx. The T score is based on 2 factors:

- The size of the primary tumor
- The growth of the primary tumor into nearby structures

HPV-negative oropharyngeal cancer forms a primary tumor that will grow larger over time. The tumor may also grow into nearby tissue as it advances. An example is growth into the flap of tissue at the base of the tongue called the epiglottis.

N score

The N score describes cancer growth in nearby lymph nodes. Most of these nodes are in your neck. Oropharyngeal cancer often spreads to lymph nodes that are next to the jugular vessels in the neck.

The N score is based on 4 factors:

- The number of lymph nodes with cancer
- The size of the lymph nodes with cancer
- Whether lymph nodes with cancer are on the same or opposite side of the neck as the primary tumor
- Cancer growth from inside a lymph node to outside the node, which is called extranodal extension

M score

The M score tells if the cancer has spread to body parts far from the oropharynx. HPV-negative oropharyngeal cancer most often spreads to the lungs. Less often, the cancer spreads far to bones and the liver.

Stages 0 through 4C

Cancer stages consist of combinations of TNM scores based on prognosis. The cancer stages for HPV-negative oropharyngeal cancer range from stage 0 to stage 4. Stage 4 is further grouped by the letters A, B, and C. Doctors write these stages as: stage 0, stage I, stage II, stage III, stage IVA, stage IVB, and stage IVC.

- Stage 0 isn't cancer but abnormal throat cells that may become cancer.
- Stages 1, 2, 3, 4A, 4B, and 4C are cancer.

The stage before any treatment is called the clinical stage. The stage after surgery is called the pathologic stage. Clinical stages of HPV-negative oropharyngeal cancer are listed in [Guide 2](#).

Guide 2

Clinical stages of HPV-negative oropharyngeal cancer

Stage 1	
T1, N0, M0	A T1 tumor is 2 cm or smaller. The cancer hasn't spread from the throat (N0, M0).
Stage 2	
T2, N0, M0	A T2 tumor is larger than T1 but not larger than 4 cm. There's no cancer spread.
Stage 3	
T1, N1, M0 T2, N1, M0	These cancers are like stage 1 or 2 but have spread to 1 lymph node (N1). The node is on the same side of the neck as the tumor. It is 3 cm or smaller.
T3, N0, M0 T3, N1, M0	A T3 tumor is larger than 4 cm or has grown into the epiglottis. Some of these cancers have spread to 1 lymph node (N1). The node is on the same side of the neck as the tumor and is 3 cm or smaller.
Stage 4A	
T4a, N0, M0 T4a, N1, M0	A T4a tumor has grown into the voice box, muscle of the tongue, or bones of the mouth (that is, medial pterygoid, hard palate, jaw). Some of these cancers have spread to 1 lymph node (N1). The node is on the same side of the neck as the tumor and is 3 cm or smaller.
T1, N2, M0 T2, N2, M0 T3, N2, M0 T4a, N2, M0	The primary tumor is any size and may have grown into the epiglottis, voice box, tongue muscle, or mouth bones. N2 means that these cancers have spread to: <ul style="list-style-type: none"> • 1 node like N1 but the node is larger than 3 cm but not larger than 6 cm, or • 2 or more nodes that are on any side of the neck and are 6 cm or smaller.
Stage 4B	
T1, N3, M0 T2, N3, M0 T3, N3, M0 T4a, N3, M0	The primary tumor is any size and may have grown into the epiglottis, voice box, tongue muscle, or mouth bones. N3 means that: <ul style="list-style-type: none"> • At least 1 lymph node with cancer is larger than 6 cm, or • The cancer has grown from inside a lymph node to outside the node.
T4b, Any N, M0	A T4b tumor has grown: <ul style="list-style-type: none"> • Into muscles or bones that move the jaw, the upper throat, or the skull, or • Around the carotid artery. Some of these cancers have spread to lymph nodes.
Stage 4C	
Any T, Any N, M1	The cancer has spread far from the oropharynx, such as to the lungs (M1).

Primary treatment

Options for primary treatment are mainly based on the cancer stage. Treatment goals can differ between cancer stages. Ask your treatment team what the goals are for your treatment. Also, ask your team what you should expect during and after treatment.

Primary treatment for early and advanced HPV-negative cancers

Early cancers are stage 1, stage 2, and stage 3 (T1 or T2). Advanced cancers are stage 3 (T3), stage 4A, and stage 4B (T1 through T4a). Options for primary treatment of early and advanced cancers are listed in [Guide 3](#).

Radiation therapy

For early cancers, radiation therapy by itself may be used as the main treatment. When used for this purpose, it is called definitive radiation therapy. The throat tumor and any lymph nodes with cancer will be treated. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

Surgery

For early and advanced cancers, surgery may be an option. The throat tumor will be removed, along with some normal-looking tissue around its rim. Also, lymph nodes from several areas in the neck may be removed. Removal of these lymph nodes is called a neck dissection. Read *Adjuvant treatment after surgery* in this chapter to learn if you will need more treatment.

Guide 3

Primary treatment for early and advanced HPV-negative cancers

Stage 1
Stage 2
Stage 3
T1, N1, M0
T2, N1, M0

The 3 options are:

- Radiation therapy then imaging as listed in [Guide 5](#)
- Surgery then more treatment if listed as needed in [Guide 7](#)
- Clinical trial

For stage 3 (T1 or T2), a fourth option may be:

- Radiation therapy with systemic therapy then imaging as listed in [Guide 5](#)

Stage 3
T3, N0, M0
T3, N1, M0
Stage 4A
Stage 4B
T1–T4a, N3, M0

The 3 options are:

- Radiation therapy with systemic therapy then imaging as listed in [Guide 5](#)
- Surgery then more treatment if listed as needed in [Guide 7](#)
- Clinical trial

Radiation therapy with systemic therapy

For advanced cancers, radiation therapy with systemic therapy is a standard option. It is also an option for early stage 3 (T1 or T2) cancer, but more research is needed to learn how well it works. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

Clinical trial

For early and advanced cancers, a clinical trial may be an option. Ask your doctors if there is a clinical trial that is right for you. Clinical trials can answer questions, such as:

- Do lower doses of radiation work as well as higher doses?
- How does proton radiation compare to photon radiation?



Learn from others on how to deal with side effects of radiation that can arise. Find out how others cope with the treatments, handling eating and weight loss issues, and products to ease discomfort.”

– Phil

Head-and-neck cancer survivor



Supportive care

Supportive care aims to improve your quality of life. It includes care for health issues caused by cancer or cancer treatment. It is also sometimes called palliative care. Supportive care is important for everyone, not just people at the end of life.

Treatment side effects

All cancer treatments can cause unwanted health issues. Such health issues are called side effects. Some side effects may be harmful to your health. Others may just be unpleasant.

Side effects depend on many factors. These factors include the treatment type, length or dose of treatment, and the person.

Ask your treatment team for a complete list of side effects of your treatments. Also, tell your treatment team about any new or worse symptoms you get. There may be ways to help you feel better. There are also ways to prevent some side effects.

Primary treatment for very advanced HPV-negative cancers

Very advanced cancers are stage 4B (T4b) and stage 4C. This section is also for earlier stages that can't be treated with surgery. Options for primary treatment of very advanced cancers are listed in [Guide 4](#).

Stage 4C is also called metastatic cancer. Some people with cancer in distant body parts also have cancer in or near the oropharynx. In this case, your doctors may have one treatment plan for the locoregional cancer and another plan for the metastases.

Guide 4

Primary treatment for very advanced HPV-negative cancers

Cancers that can't be treated with surgery including:
Stage 4B
T4b,Any N, M0

For a performance status of 0 or 1, the 3 options are:

- Clinical trial (preferred)
- Radiation therapy with systemic therapy then imaging as listed in [Guide 5](#)
- Induction systemic therapy followed by either:
 - Radiation therapy then imaging as listed in [Guide 5](#), or
 - Radiation therapy with systemic therapy then imaging as listed in [Guide 5](#)

For a performance status of 2, the 3 options are:

- Clinical trial (preferred)
- Radiation therapy then imaging as listed in [Guide 5](#)
- Radiation therapy with systemic therapy then imaging as listed in [Guide 5](#)

For a performance status of 3 or 4, the 4 options are:

- Clinical trial (preferred)
- Radiation therapy used for supportive care
- Systemic therapy with one drug (single agent)
- Supportive care

Stage 4C

For a performance status of 0 or 1, the 4 options are:

- Clinical trial (preferred)
- Systemic therapy (single or multiple agents)
- If metastases are limited: Surgery, radiation therapy, or radiation therapy with systemic therapy
- Supportive care

For a performance status of 2, the 3 options are:

- Clinical trial (preferred)
- Single-agent systemic therapy
- Supportive care

For a performance status of 3 or 4, the 2 options are:

- Clinical trial (preferred)
- Supportive care

Performance status

The treatment options in Guide 4 are grouped by performance status. Performance status is your ability to do daily activities. The Eastern Cooperative Oncology Group (ECOG) Performance Status is a common scoring system. It consists of five scores.

- A score of 0 means you are fully active.
- A score of 1 means you are able to do all self-care activities but are unable to do hard physical work.
- A score of 2 means you are able to do all self-care activities and spend most of waking time out of bed but are unable to do any work.
- A score of 3 means you are unable to do all self-care activities and any work and spend most of waking time in bed.
- A score of 4 means you are fully disabled.

Clinical trial

A clinical trial is preferred by NCCN experts for all very advanced cancers. Ask your doctors if there is a clinical trial that is right for you.

Radiation therapy with systemic therapy

For stage 4B (T4b), radiation therapy with systemic therapy may be an option if you are healthy enough. It may also be an option for stage 4C cancer that isn't widespread. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

For stage 4B (T4b), a less common approach is to receive only systemic therapy as the first treatment. This is called induction systemic therapy. It may be followed by radiation therapy with or without systemic therapy. Read *Surgery*

after radiation therapy in this chapter to learn if you will need more treatment.

Radiation therapy

For stage 4B (T4b), radiation therapy by itself may be an option if systemic treatment may be harmful for you. When used as the main treatment, it is called definitive radiation therapy. Radiation therapy may also be an option for stage 4C cancer that isn't widespread. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

Systemic therapy

Systemic therapy by itself may be used as the main treatment. Sometimes, more than one drug is used because drugs differ in the way they work. Other times, only one drug is used so side effects won't be severe.

Surgery for metastases

Surgery may be an option for some stage 4C cancers. The metastatic cancer must be in a confined spot so all of it can be removed. The goal is to control the growth of cancer and prevent symptoms.

Supportive care

Cancer treatment may be too harmful if your performance score is high. In this case, supportive care will be given. It aims to improve your quality of life. It is sometimes called palliative care.

Supportive care includes care for health issues caused by cancer. An example is the use of radiation therapy to relieve pain. Talk with your treatment team to plan the best supportive care for you.

Adjuvant treatment

When cure is the goal of treatment, adjuvant treatment may follow primary treatment. After primary treatment, there still may be tiny amounts of cancer in your body. Adjuvant treatment targets areas that may have cancer. It helps stop the cancer from coming back.

Surgery after radiation therapy

A neck dissection is a surgery that removes lymph nodes that likely have cancer. For some people, it may help stop a cancer from returning in the neck. This section explains who will likely benefit from a neck dissection or other surgery after radiation therapy.

Cancer tests

After radiation therapy, your doctor will assess the treatment results. It may take weeks for the true results to be seen. So, your doctor may wait 4 to 8 weeks after treatment to do a clinical assessment.

A clinical assessment may include:

- Questions about symptoms
- A physical exam
- An endoscopy of your throat

You will also undergo imaging to assess treatment results. The types of imaging used include computed tomography (CT), positron emission tomography and CT (PET/CT), and magnetic resonance imaging (MRI). Options for imaging based on the clinical assessment are listed in [Guide 5](#).

Who needs surgery?

Your doctors will decide whether surgery is needed based on test results. Surgery is not needed if all tests do not detect cancer. You may need more imaging to help guide treatment decisions. If tests clearly detect cancer, surgery will be needed. [See Guide 6](#) for a summary of who will need surgery.

Guide 5

Imaging after radiation therapy

Your doctor did not find signs of cancer during the clinical assessment

The 2 options are:

- FDG PET/CT at least 12 weeks after treatment (preferred); if cancer is detected, get CT with contrast or MRI with contrast
- CT with contrast, MRI with contrast, or both at 8 to 12 weeks after treatment

Your doctor did find signs of cancer during the clinical assessment

The 2 options are:

- CT with contrast or MRI with contrast
- FDG PET/CT

Guide 6

Surgery after radiation therapy

Imaging confirmed no signs of cancer	Surgery is not needed. Start follow-up care.
Your doctor did not find signs of cancer but CT or MRI showed signs of cancer	You may need a neck dissection but your doctor may first order FDG CT/PET at least 12 weeks after treatment to help guide treatment decisions.
Your doctor did not find signs of cancer and PET/CT results were unclear	You may not need a neck dissection, but your doctor may order another PET/CT at 3 to 6 months to help guide treatment decisions.
Your doctor did not find signs of cancer but PET/CT showed signs of cancer	A biopsy may be done to confirm there is cancer. You may have surgery on the throat, a neck dissection, or both.
Imaging confirmed signs of cancer	You may have surgery on the throat, a neck dissection, or both. If surgery is not an option, read Guide 4 for treatment options.

Adjuvant treatment after surgery

If you had surgery, you may need adjuvant treatment. In this section, adjuvant treatment is grouped by the cancer stage and adverse features. [See Guide 7](#) for options.

Adverse factors include:

- Cancer growth from inside a lymph node to outside the node (extranodal extension)
- Cancer in the normal-looking tissue that was removed with the tumor (surgical margins)
- High pathologic T or N scores
- Cancer in lymph nodes that are in the lower neck and in the back of the neck
- Cancer growth to nerves or vessels

Guide 7

Adjuvant treatment after surgery for HPV-negative cancers

Stage 1 Stage 2 Stage 3 T1, N1, M0 T2, N1, M0	If no adverse features are found, adjuvant treatment is not needed. <ul style="list-style-type: none"> • Start follow-up care
	If the cancer has grown from inside a lymph node to outside the node, an option is: <ul style="list-style-type: none"> • Radiation therapy with systemic therapy
	If the cancer has <u>not</u> grown from inside a lymph node to outside the node but cancer was found in the normal-looking tissue removed with the tumor, there are 3 options: <ul style="list-style-type: none"> • Surgery • Radiation therapy • Radiation therapy with systemic therapy
	If there are other adverse factors, the 2 options are: <ul style="list-style-type: none"> • Radiation therapy • Radiation therapy with systemic therapy
Stage 3 T3, N0, M0 T3, N1, M0 Stage 4A Stage 4B T1–T4a, N3, M0	If no adverse factors are found, you may have two options: <ul style="list-style-type: none"> • Radiation therapy • Start follow-up care if cancer is downstaged to an early stage
	If cancer was found in the normal-looking tissue around the tumor or cancer has grown from inside a node to outside the node, the option is: <ul style="list-style-type: none"> • Radiation therapy with systemic therapy
	If there are other adverse factors, the 2 options are: <ul style="list-style-type: none"> • Radiation therapy • Radiation therapy with systemic therapy

Review

- Oropharyngeal cancer that is not related to HPV is called HPV negative.
- The goal of treatment is to either cure the cancer or stop the cancer from growing.
- Stages of HPV-negative oropharyngeal cancer are stage 1, stage 2, stage 3, stage 4A, stage 4B, and stage 4C.
- Primary treatment is based on the cancer stage and other factors.
- Early and advanced cancers are often treated with local treatment. Local treatments include radiation therapy, surgery, and radiation therapy with systemic therapy.
- Very advanced cancers are often treated with systemic therapy. Radiation therapy may also be part of treatment if the cancer is within a confined area.
- A clinical trial is listed as an option for all stages. Ask your treatment team if there is a clinical trial that is right for you.
- You may undergo a neck dissection if there's cancer in your neck lymph nodes after radiation therapy.
- You may receive more treatment after surgery if there are signs that cancer is still in your body.



I feel that after all the treatment is done, the healing is the hardest part.”

– Richard

Head-and-neck cancer survivor

4

HPV-positive cancer

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This chapter is about initial treatment for HPV-positive oropharyngeal cancer. Treatment options are based on the cancer stage and other factors. Discuss with your doctors which options in this chapter are right for you.

Overview

Oropharyngeal cancers that are related to human papillomavirus (HPV) are a different disease than cancers unrelated to HPV. Oropharyngeal cancer that is related to HPV is called HPV positive. This chapter is about the first treatments for HPV-positive oropharyngeal cancer.

Treatment for oropharyngeal cancer includes treatment for the cancer and support for you. Most HPV-positive oropharyngeal cancers are cured. If a cure is not possible, the goals of treatment are to reduce symptoms, control cancer growth, and extend life. During and after cancer treatment, you may meet with health providers whose focus is to improve your quality of life.

Multidisciplinary team

A multidisciplinary team consists of experts from different fields of medicine. Examples of experts include a head-and-neck surgeon, radiation oncologist, and medical oncologist. It is important that your information be reviewed by a multidisciplinary team.

You are part of the team. The experts should explain their preferred treatment plan to you. Ask about the pros and cons of the plan. Ask

about any other treatment options. Tell your team your goals and wishes for treatment.

Cancer stage

Your doctors will plan your initial treatment based on many factors. These factors include your age and level of fitness. Treatment will also be based on the cancer. A very important factor is the cancer stage. The stages of HPV-positive oropharyngeal cancer are explained in the next section.

Primary treatment

Primary treatment is the main treatment of cancer. It may consist of local treatment, systemic treatment, or both.

- A local treatment targets cancer in a confined area. It includes radiation therapy and surgery.
- Systemic treatment treats cancer throughout the body. It includes chemotherapy, targeted therapy, and immunotherapy.

A common treatment for oropharyngeal cancer is radiation therapy with systemic therapy. Both treatments are given during the same time period. Some people call it “concurrent radiation therapy and systemic therapy.”

Adjuvant treatment

Adjuvant treatment helps stop a cancer from coming back. It is sometimes given after surgery or radiation therapy. At the end of this chapter, who will likely need adjuvant treatment and which treatments are options are explained.

Cancer stage

The cancer stage is a rating of the extent of cancer in your body. Your doctors use it for many things. It is used to assess the outlook of the cancer (prognosis). It is used to plan treatment. It is also used for research.

The American Joint Committee on Cancer (AJCC) staging system is used to stage oropharyngeal cancer. In this system, the letters T, N, and M describe the extent of the cancer.

T score

The T score describes the growth of the primary tumor. The primary tumor is a mass of cancer cells in the oropharynx. The T score is based on 3 factors:

- Whether there is a primary tumor
- The size of the primary tumor
- The growth of the primary tumor into nearby structures

HPV-positive oropharyngeal cancer often forms a tumor in the oropharynx. It may be hard to find. The tumor may invade nearby tissue, such as the epiglottis. The epiglottis is a flap of tissue at the base of the tongue.

N score

The N score describes cancer growth in nearby lymph nodes. Most of these nodes are in your neck. Oropharyngeal cancer often spreads to lymph nodes that are next to the jugular vessels in the neck.

The N score is based on 3 factors:

- Whether any lymph nodes have cancer
- The size of the lymph nodes with cancer
- Whether lymph nodes with cancer are on the same or opposite side of the neck as the primary tumor

M score

The M score tells if the cancer has spread to body parts far from the oropharynx. HPV-positive oropharyngeal cancer most often spreads to the lungs. Less often, the cancer spreads far to bones and the liver.

Stages 1 through 4

Cancer stages consist of combinations of TNM scores based on prognosis. The cancer stages for HPV-positive oropharyngeal cancer range from stage 1 to stage 4. Doctors write these stages as—stage I, stage II, stage III, and stage IV.

The stage before any treatment is called the clinical stage. The stage after surgery is called the pathologic stage. Clinical stages of HPV-positive oropharyngeal cancer are listed in [Guide 8](#).

Guide 8

Clinical stages of HPV-positive oropharyngeal cancer

Stage 1	
T1, N0, M0 T2, N0, M0	A T1 tumor is 2 cm or smaller. A T2 tumor is larger but not larger than 4 cm. The cancer has not spread from the throat (N0, M0).
T0, N1, M0 T1, N1, M0 T2, N1, M0	A primary tumor is not found (T0) or is 4 cm or smaller (T1, T2). The cancer has spread to nodes that are on the same side of the neck as the tumor (N1). Nodes with cancer are 6 cm or smaller.
Stage 2	
T0, N2, M0 T1, N2, M0 T2, N2, M0	A primary tumor is not found (T0) or is 4 cm or smaller (T1, T2). The cancer has spread to lymph nodes on the opposite side of the neck from the tumor (N2). These nodes are 6 cm or smaller.
T3, N0, M0 T3, N1, M0 T3, N2, M0	A T3 tumor is larger than 4 cm or has grown into the epiglottis. Some of these cancers have spread to lymph nodes (N1 or N2). Nodes with cancer are 6 cm or smaller.
Stage 3	
T0, N3, M0 T1, N3, M0 T2, N3, M0 T3, N3, M0	A primary tumor is not found (T0). If found, the tumor is any size or has grown into the epiglottis (T1, T2, T3). The cancer has spread to nearby lymph nodes. At least 1 lymph node with cancer is larger than 6 cm (N3).
T4, N0, M0 T4, N1, M0 T4, N2, M0 T4, N3, M0	A T4 tumor has grown into the voice box, muscle of the tongue, bones of the mouth (that is, medial pterygoid, hard palate, jaw), or farther into the neck or head. Some of these cancers have spread to lymph nodes (N1, N2, N3).
Stage 4	
Any T, Any N, M1	The cancer has spread far from the oropharynx, such as to the lungs (M1).

Primary treatment

Options for primary treatment are mainly based on the cancer stage. Treatment goals can differ between cancer stages. Ask your treatment team what the goals are for your treatment. Also, ask your treatment team what you should expect during and after treatment.

Primary treatment for early and advanced HPV-positive cancers

Early and advanced cancers are stage 1, stage 2, and stage 3. Treatment options for stage 1 are based on the extent of cancer growth in lymph nodes. Some stage 1 cancers

are treated like stage 2 and stage 3 cancers. Options for primary treatment of early and advanced cancers are listed in [Guide 9](#).

Radiation therapy

Radiation therapy by itself is an option for:

- Stage 1 (N0), and
- Stage 1 (N1) with spread to 1 lymph node that is 3 cm or smaller.

When used as the main treatment, it is called definitive radiation therapy. The throat tumor and any lymph nodes with cancer will be treated. Read *Surgery after radiation therapy*

Guide 9

Primary treatment for early and advanced HPV-positive cancers

Stage 1 (N0) with no spread to lymph nodes

The 3 options are:

- Radiation therapy then imaging as listed in [Guide 11](#)
- Surgery then more treatment if listed as needed in [Guide 13](#)
- Clinical trial

Stage 1 (N1) with spread to:

- 1 lymph node that is 3 cm or smaller

The 4 options are:

- Radiation therapy then imaging as listed in [Guide 11](#)
- Surgery then more treatment if listed as needed in [Guide 13](#)
- Radiation therapy with systemic therapy then imaging as listed in [Guide 11](#)
- Clinical trial

Stage 1 (N1) with spread to:

- 1 lymph node that is larger than 3 cm, or
- 2 or more lymph nodes

The 3 options are:

- Radiation therapy with systemic therapy then imaging as listed in [Guide 11](#)
- Surgery then more treatment if listed as needed in [Guide 13](#)
- Clinical trial

Stage 2

Stage 3

in this chapter to learn if you will need more treatment.

Surgery

For stages 1 through 3, surgery is an option. The throat tumor will be removed, along with some normal-looking tissue around its rim. Also, lymph nodes from several areas in the neck may be removed. Removal of these lymph nodes is called a neck dissection. Read *Adjuvant treatment after surgery* in this chapter to learn if you will need more treatment.

Radiation therapy with systemic therapy

Radiation therapy with systemic therapy is a standard option for:

- Stage 1 (N1) with spread to 1 lymph node that is larger than 3 cm
- Stage 1 (N1) with spread to 2 or more lymph nodes
- Stage 2
- Stage 3

More research is needed to learn how well this combined treatment works for stage 1 with a lymph node 3 cm or smaller. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

Clinical trial

For early and advanced cancers, a clinical trial may be an option. Ask your doctors if there is a clinical trial that is right for you. Clinical trials can answer questions, such as:

- Do lower doses of radiation work as well as higher doses?
- How does proton radiation compare to photon radiation?



Supportive care

Supportive care aims to improve your quality of life. It includes care for health issues caused by cancer or cancer treatment. It is also sometimes called palliative care. Supportive care is important for everyone, not just people at the end of life.

Treatment side effects

All cancer treatments can cause unwanted health issues. Such health issues are called side effects. Some side effects may be harmful to your health. Others may just be unpleasant.

Side effects depend on many factors. These factors include the treatment type, length or dose of treatment, and the person.

Ask your treatment team for a complete list of side effects of your treatments. Also, tell your treatment team about any new or worse symptoms you get. There may be ways to help you feel better. There are also ways to prevent some side effects.

Primary treatment for very advanced HPV-positive cancers

Very advanced cancers are stage 4. These cancers are also called metastatic cancers. Treatment options for very advanced cancers are listed in [Guide 10](#).

Some people with cancer in distant body parts also have cancer in or near the oropharynx. In this case, your doctors may have one treatment plan for the locoregional cancer and another plan for the metastases.

Stage 1 through 3 cancers that can't be treated with surgery are also treated as very advanced

Guide 10

Primary treatment for very advanced HPV-positive cancers

Stages 1, 2, 3 that can't be treated with surgery	<p>For a performance status of 0 or 1, the 3 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Radiation therapy with systemic therapy then imaging as listed in Guide 11 • Induction systemic therapy followed by either: <ul style="list-style-type: none"> • Radiation therapy then imaging as listed in Guide 11, or • Radiation therapy with systemic therapy then imaging as listed in Guide 11 <hr/> <p>For a performance status of 2, the 3 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Radiation therapy then imaging as listed in Guide 11 • Radiation therapy with systemic therapy then imaging as listed in Guide 11 <hr/> <p>For a performance status of 3 or 4, the 4 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Radiation therapy used for supportive care • Systemic therapy with one drug (single agent) • Supportive care
Stage 4	<p>For a performance status of 0 or 1, the 4 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Systemic therapy (single or multiple agents) • If metastases are limited: Surgery, radiation therapy, or radiation therapy with systemic therapy • Supportive care <hr/> <p>For a performance status of 2, the 3 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Single-agent systemic therapy • Supportive care <hr/> <p>For a performance status of 3 or 4, the 2 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Supportive care

cancers. Surgery may not be an option because of your health or where the cancer has grown.

Performance status

The treatment options in Guide 10 are grouped by performance status. Performance status is your ability to do daily activities. The Eastern Cooperative Oncology Group (ECOG) Performance Status is a common scoring system. It consists of five scores.

- A score of 0 means you are fully active.
- A score of 1 means you are able to do all self-care activities but are unable to do hard physical work.
- A score of 2 means you are able to do all self-care activities and spend most of waking time out of bed but are unable to do any work.
- A score of 3 means you are unable to do all self-care activities and any work and spend most of waking time in bed.
- A score of 4 means you are fully disabled.

Clinical trial

A clinical trial is preferred by NCCN experts for all very advanced cancers. Ask your doctors if there is a clinical trial that is right for you.

Radiation therapy with systemic therapy

For some stage 1 (N1) and all stage 2 and 3 cancers, radiation therapy with systemic therapy may be an option if you are healthy enough. It may also be an option for stage 4 cancer that isn't widespread. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

For stages 1 through 3, another approach is to receive only systemic therapy as the first

treatment. This is called induction systemic therapy. It may be followed by radiation therapy with or without systemic therapy. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

Radiation therapy

For stages 1 through 3, radiation therapy by itself may be an option if systemic treatment may be harmful for you. When used as the main treatment, it is called definitive radiation therapy. Radiation therapy may also be an option for stage 4 cancer that isn't widespread. Read *Surgery after radiation therapy* in this chapter to learn if you will need more treatment.

Systemic therapy

Systemic therapy by itself may be used as the main treatment. Sometimes, more than one drug is used because drugs differ in the way they work. Other times, only one drug is used so side effects won't be severe.

Surgery for metastases

Surgery may be an option for some stage 4 cancers. The metastatic cancer must be in a confined spot so all of it can be removed. The goal is to control the growth of cancer and prevent symptoms.

Supportive care

Cancer treatment may be too harmful if your performance score is high. In this case, supportive care will be given. It aims to improve your quality of life. It is sometimes called palliative care.

Supportive care includes care for health issues caused by cancer. An example is the use of radiation therapy to relieve pain. Talk with your treatment team to plan the best supportive care for you.

Adjuvant treatment

When cure is the goal of treatment, adjuvant treatment may follow primary treatment. After primary treatment, there still may be tiny amounts of cancer in your body. Adjuvant treatment targets areas that may have cancer. It helps stop the cancer from coming back.

Surgery after radiation therapy

A neck dissection is a surgery that removes lymph nodes that likely have cancer. For some people, it may help stop a cancer from returning in the neck. This section explains who will likely benefit from a neck dissection or other surgery after radiation therapy.

Cancer tests

After radiation therapy, your doctor will assess the treatment results. It may take weeks for the true results to be seen. So, your doctor may wait 4 to 8 weeks after treatment to do a clinical assessment.

A clinical assessment may include:

- Questions about symptoms
- A physical exam
- An endoscopy of your throat

You will also undergo imaging to assess treatment results. The types of imaging used include computed tomography (CT), positron emission tomography and CT (PET/CT), and magnetic resonance imaging (MRI). Options for imaging based on the clinical assessment are listed in [Guide 11](#).

Who needs surgery?

Your doctors will decide whether surgery is needed based on test results. Surgery is not needed if all tests do not detect cancer. You may need more imaging to help guide treatment decisions. If tests clearly detect cancer, surgery will be needed. [See Guide 12](#) for a summary of who will need surgery.



I could have worried, could have lived in fear every single day, if I chose to. I had no idea what the outcome was going to be. But what was going to happen was going to happen, regardless of my worrying or my fear, so why do it?”

– Steve

HPV-related tongue and neck cancer

Guide 11**Imaging after radiation therapy**

Your doctor did not find signs of cancer during the clinical assessment	<p>The 2 options are:</p> <ul style="list-style-type: none"> • FDG PET/CT at least 12 weeks after treatment (preferred); if cancer is detected, get CT with contrast or MRI with contrast • CT with contrast, MRI with contrast, or both at 8 to 12 weeks after treatment
Your doctor did find signs of cancer during the clinical assessment	<p>The 2 options are:</p> <ul style="list-style-type: none"> • CT with contrast or MRI with contrast • FDG PET/CT

Guide 12**Surgery after radiation therapy**

Imaging confirmed no signs of cancer	Surgery is not needed. Start follow-up care.
Your doctor did not find signs of cancer but CT or MRI showed signs of cancer	You may need a neck dissection but your doctor may first order FDG CT/PET at least 12 weeks after treatment to help guide treatment decisions.
Your doctor did not find signs of cancer and PET/CT results were unclear	You may not need a neck dissection, but your doctor may order another PET/CT at 3 to 6 months to help guide treatment decisions.
Your doctor did not find signs of cancer but PET/CT showed signs of cancer	A biopsy may be done to confirm there is cancer. You may have surgery on the throat, a neck dissection, or both.
Imaging confirmed signs of cancer	You may have surgery on the throat, a neck dissection, or both. If surgery is not an option, read Guide 10 for treatment options.

Adjuvant treatment after surgery

If you had surgery, you may have adjuvant treatment afterward. Options for adjuvant treatment are listed in [Guide 13](#).

In this section, adjuvant treatment is based partly on the cancer stage and adverse features. Adverse factors include:

- Cancer growth from inside a lymph node to outside the node (extranodal extension)
- Cancer in the normal-looking tissue that was removed with the tumor (surgical margins)
- High pathologic T or N scores
- Cancer in lymph nodes that are in the lower neck and in the back of the neck
- Cancer growth to nerves or vessels

Guide 13**Adjuvant treatment after surgery for HPV-positive cancer**

Stage 1 (N0) with no spread to lymph nodes Stage 1 (N1) with spread to: <ul style="list-style-type: none"> • 1 lymph node that is 3 cm or smaller 	<p>If no adverse features are found, adjuvant treatment is not needed.</p> <ul style="list-style-type: none"> • Start follow-up care
	<p>If the cancer has grown from inside a lymph node to outside the node, there are 2 options:</p> <ul style="list-style-type: none"> • Radiation therapy with systemic therapy • Radiation therapy
	<p>If the cancer has <u>not</u> grown from inside a lymph node to outside the node, but cancer was found in the normal-looking tissue removed with the tumor, there are 3 options:</p> <ul style="list-style-type: none"> • Surgery • Radiation therapy with systemic therapy • Radiation therapy
	<p>If there are other adverse factors, there are 2 options:</p> <ul style="list-style-type: none"> • Radiation therapy • Radiation therapy with systemic therapy
Stage 1 (N1) with spread to: <ul style="list-style-type: none"> • 1 lymph node that is larger than 3 cm, or • 2 or more lymph nodes Stage 2 Stage 3	<p>If no adverse features are found, the option is:</p> <ul style="list-style-type: none"> • Start follow-up care
	<p>If cancer was found in the normal-looking tissue around the tumor or cancer has grown from inside a node to outside the node, the option is:</p> <ul style="list-style-type: none"> • Radiation therapy with systemic therapy
	<p>If there are other adverse factors, there are 2 options:</p> <ul style="list-style-type: none"> • Radiation therapy • Radiation therapy with systemic therapy

IN DEPTH

Systemic therapy regimens

Systemic therapy used
with other treatment:

Regimens used with radiation therapy for primary treatment

Preferred

- High-dose cisplatin
- Carboplatin, infusional 5-FU

Other

- 5-FU, hydroxyurea
- Carboplatin, paclitaxel
- Cetuximab
- Cisplatin, infusional 5-FU
- Cisplatin, paclitaxel
- Weekly cisplatin

Regimens used with radiation therapy for adjuvant treatment

Preferred

- Cisplatin

Other

- None

Induction regimens

Preferred

- Docetaxel, cisplatin, 5-FU

Other

- Paclitaxel, cisplatin, infusional 5-FU

Regimens used with radiation therapy after induction

Preferred

- Weekly carboplatin
- Weekly cisplatin

Other

- Weekly cetuximab

Systemic therapy
used alone:

First-line regimens

Preferred

- Cetuximab, (cisplatin or carboplatin), 5-FU
- Pembrolizumab, (cisplatin or carboplatin), 5-FU
- Pembrolizumab for cancers with PD-L1 marker

Other

- Cisplatin, cetuximab
- (Cisplatin or carboplatin), docetaxel
- (Cisplatin or carboplatin), paclitaxel
- Cisplatin, 5-FU
- (Cisplatin or carboplatin), docetaxel, cetuximab
- (Cisplatin or carboplatin), paclitaxel, cetuximab
- Cisplatin
- Carboplatin
- Paclitaxel
- Docetaxel
- 5-FU
- Methotrexate
- Cetuximab
- Gemcitabine
- Capecitabine

Second-line regimens

Preferred

- Nivolumab if platinum therapy failed
- Pembrolizumab if platinum therapy failed

Other

- Cisplatin, cetuximab
- Cisplatin, (docetaxel or paclitaxel)
- Carboplatin, (docetaxel or paclitaxel)

Review

- Oropharyngeal cancer that is related to HPV is called HPV positive.
- The goal of treatment is to either cure the cancer or stop the cancer from growing.
- Stages of HPV-positive oropharyngeal cancer are stage 1, stage 2, stage 3, and stage 4.
- Primary treatment is based on the cancer stage and other factors.
- A clinical trial is listed as an option for all stages. Ask your treatment team if there is a clinical trial that is right for you.
- You may undergo a neck dissection if cancer remains in your neck lymph nodes after radiation therapy.
- You may receive more treatment after surgery if there are signs that cancer may remain in your body.



The fears of the unknown and the possible side effects, I've lived through it and I'm proof that you can win this battle!"

– Debbie

Head-and-neck cancer survivor

5

Follow-up care

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- 49 Managing side effects
- 50 Disease prevention
- 50 Review



Follow-up care is important for your long-term health. It is started when there are no signs of cancer at the end of treatment. This chapter reviews key parts of follow-up care.

At the end of cancer treatment, your cancer doctor will provide you with a care plan. You may need to see many types of health care providers. Examples include your primary care doctor, a speech-language pathologist, an oncologic dentist, and your cancer doctor. Your providers should work together to meet your needs.

Cancer tests

While oropharyngeal cancer can be cured, it is very important to monitor for the return of the cancer. The return of cancer is called a recurrence. It is also important to be checked for other types of cancer.

Tests for recurrence

Follow-up care should include a schedule of tests for recurrence. Routine testing for cancer recurrence is called surveillance. Early detection will allow for timely treatment.

Follow-up visits

You will meet with your cancer doctor often after treatment ends. At these visits, your doctor may perform the following:

- Medical history
- Physical exam
- Endoscopy of your throat

Six years after treatment, you may see your doctor only once a year. See [Guide 14](#) for a schedule of visits.

Imaging

Imaging may be done to assess for relapse.

- Within 6 months after treatment has ended, your doctor may repeat the imaging that was done before treatment.
- Your doctor may order imaging on a regular basis if some parts of your neck or head can't be seen on exam.
- If signs of cancer appear, imaging will be needed at that time.

Guide 14 Follow-up visits by year after treatment

Year 1	Visits every 1 to 3 months
Year 2	Visits every 2 to 6 months
Year 3 to 5	Visits every 4 to 8 months
Year 6 and on	Visits every 12 months

Cancer screening

You may be at risk for a second cancer. A second cancer is a possible late effect of some cancer treatments. Also, your risk for cancer increases as you age. If you smoke, your chance for cancer increases the longer you smoke. Ask your doctor about your risk for another cancer.

If you have a high risk for certain cancers, you may enroll in a screening program. Cancer screening is routine testing for cancer

before cancer symptoms start. There is not a screening program for every type of cancer.

There are cancer screening programs for:

- Prostate cancer in men
- Breast or cervical cancer in women
- Colorectal cancer
- Lung cancer

People at high risk for lung cancer should enroll in a screening program. Visit this webpage to read about lung cancer screening: [nccn.org/patients/guidelines/cancers.aspx#lungScreening](https://www.nccn.org/patients/guidelines/cancers.aspx#lungScreening).



I am alive and hopeful. I want others to know what to expect during and after treatment so they can focus on treatment and enjoy living after treatment. I recall not caring much about the side effects when discussing treatment, as my focus was on living. Post treatment—when you are alive—then side effects have some importance.”

– Lance

Head-and-neck cancer survivor

Managing side effects

Side effects are an unhealthy or unpleasant physical or emotional response to treatment. Some side effects appear shortly after cancer treatment starts and quickly resolve after treatment ends. Other side effects are long-term or may appear years later.

At follow-up visits, your doctor will assess for side effects. Tell your doctor about any new or worse symptoms. Side effects that may occur after treatment include:

- Vision or hearing problems
- Trouble talking or swallowing
- Tiredness
- Swelling
- Dry nose and mouth
- Pain

Examples of ways to prevent or treat side effects are:

- You may receive thyroid hormone replacement for thyroid problems.
- You may receive treatment for ear infections or pain.
- A dentist can help you cope with dry mouth.
- A speech-language pathologist can improve your speech or swallowing.
- A dietician can help you get good nutrition.
- Mental health providers can help you quit smoking and limit alcohol.
- Mental health providers can also treat depression and anxiety.

Disease prevention

Another part of follow-up care is to prevent diseases. Such care can include getting immunization shots for the flu, herpes, shingles, and other diseases. Dental cleaning and exams on a regular basis can prevent disease, too.

It's important to start or keep a healthy lifestyle. Healthy living may improve your health and well-being. It may also help prevent the cancer from returning. Work with your treatment team to set goals and make plans for healthy living.

Common goals for healthy living include:

- Seeing a primary care provider on a regular basis
- Limiting alcohol use
- Not using tobacco products
- Using sun protection
- Maintaining a healthy weight
- Eating a balanced diet
- Drinking enough fluids
- Exercising

Review

- Follow-up care is important for your long-term health. It is started when there are no signs of cancer at the end of treatment. During follow-up care, you may see many types of health care providers.
- Your cancer doctor will monitor for a return of oropharyngeal cancer. Early detection will allow for timely treatment. You will also be checked for other cancers. If you have

a high risk for certain cancers, you may enroll in a screening program.

- Some side effects of treatment are long-term or may appear years later. At follow-up visits, your doctor will assess for side effects. Tell your doctor about any new or worse symptoms. There may be ways to prevent or treat side effects.
- Preventing diseases is a part of follow-up care. Such care can include getting immunization shots and dental cleaning. Healthy living may improve your health and prevent disease.



It is a very long, trying and difficult treatment to have to endure. I did not think I would ever get to the other side of it. But I am now over a year past treatment and doing great.”

– Herb

Head-and-neck cancer survivor

6

Recurrent or persistent cancer

52 Locoregional cancers

54 Metastatic cancers

56 Review



Read this chapter to learn about treatment options for recurrent or persistent cancer. Options are based on the extent of the cancer and other factors. Talk with your doctors about which options are right for you.

What are recurrent and persistent cancers?

- Recurrent cancer is cancer that comes back after a cancer-free time period.
- Persistent cancer is cancer that remains in the body after treatment.

Recurrent and persistent cancers are treated alike. Treatment partly depends on the extent of the cancer. In this chapter, treatment options are grouped by extent:

- Locoregional cancers
- Metastatic cancers

Locoregional cancers have not spread far from the oropharynx. Examples are cancers that are in the oropharynx only or have spread only to lymph nodes in the neck.

Metastatic cancers have spread far from the oropharynx. Body parts far from the oropharynx include the lung, liver, and spine.

Locoregional cancers

In this section, treatment for locoregional cancers is based on two important factors. One factor is whether the cancer can be fully and safely removed by surgery. Another factor is whether you had radiation therapy in the past. Options for locoregional cancer are listed in [Guide 15](#).

Surgery is an option

The goal of surgery is to remove all the cancer. To do so, the tumor is removed, along with some normal-looking tissue around its rim. The normal-looking tissue is called the surgical margin.

More treatment may be given after surgery to treat any cancer that remains. Treatment for this purpose is called adjuvant treatment. It helps stop the cancer from coming back.

Radiation therapy is commonly used for adjuvant treatment. Systemic therapy may be added. There are limits to how much radiation a body part can safely receive. NCCN experts prefer that a second course of radiation therapy be received within a clinical trial.

Besides surgery, radiation therapy with systemic therapy may be an option if you haven't had radiation therapy before. You must be healthy enough to receive the combined treatment.

Surgery is not an option

Instead of surgery, local treatment with radiation therapy may be an option. Systemic therapy may be added if you are healthy enough. There are limits to how much radiation a body part can safely receive. NCCN experts prefer that a

Guide 15

Treatment for recurrent or persistent, locoregional cancers

Surgery is an option	<p>If you have had radiation therapy, the option is:</p> <ul style="list-style-type: none"> • Surgery followed by one of these: <ul style="list-style-type: none"> • No further treatment if all the cancer was likely removed or if the area can't be treated with radiation again • Radiation therapy with or without systemic therapy; receiving treatment within a clinical trial is preferred <hr/> <p>If you haven't had radiation therapy, the 2 options are:</p> <ul style="list-style-type: none"> • Surgery followed by one of these: <ul style="list-style-type: none"> • No further treatment if all the cancer was likely removed • Radiation therapy with systemic therapy • Radiation therapy • Radiation therapy with systemic therapy
Surgery is not an option	<p>If you have had radiation therapy, the 3 options are:</p> <ul style="list-style-type: none"> • Radiation therapy with or without systemic therapy; receiving treatment within a clinical trial is preferred • Systemic therapy • Supportive care <hr/> <p>If you haven't had radiation therapy, the 6 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Radiation therapy with systemic therapy • Induction systemic therapy followed by either radiation therapy with or without systemic therapy • Radiation therapy • Single-agent systemic therapy • Supportive care including radiation therapy

second course of radiation therapy be received within a clinical trial.

If you haven't had radiation therapy before, another approach is to receive only systemic therapy as the first treatment. This is called induction systemic therapy. It may be followed by radiation therapy with or without systemic therapy.

Systemic therapy by itself is often used when local treatment is not an option. If you are healthy enough, regimens may contain more than one cancer drug. If your health is poor, your doctor may prescribe one cancer drug for your safety.

A clinical trial may be an option. Ask your doctors if there's a clinical trial that is right for you. A clinical trial may test which current treatment is best or may test a new treatment.

Supportive care aims to improve your quality of life. It is sometimes called palliative care. The goal is to prevent or relieve symptoms instead of cure or control the cancer. Radiation therapy may be used to relieve symptoms.



Having someone to talk to who had gone through the same thing was an enormous help to me.”

– Lawrie

Head-and-neck cancer survivor

Metastatic cancers

This section is about treatment for recurrent or persistent metastases. Some people with cancer in distant body parts also have cancer in or near the oropharynx. In this case, your doctors may have one treatment plan for the locoregional cancer and another plan for the metastases. Treatment options for metastases are listed in [Guide 16](#).

Performance status

The treatment options listed in Guide 16 are based on performance status. Performance status is your ability to do daily activities. The Eastern Cooperative Oncology Group (ECOG) Performance Status is a common scoring system.

The ECOG scale consists of five scores:

- A score of 0 means you are fully active.
- A score of 1 means you are able to do all self-care activities but are unable to do hard physical work.
- A score of 2 means you are able to do all self-care activities and spend most of waking time out of bed but are unable to do any work.
- A score of 3 means you are unable to do all self-care activities and any work and spend most of waking time in bed.
- A score of 4 means you are fully disabled.

Clinical trial

A clinical trial is preferred by NCCN experts for metastatic cancer. Ask your doctors if there is a clinical trial that is right for you.

Guide 16**Treatment for recurrent or persistent metastases**

Performance status of 0 or 1	<p>The 4 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Systemic therapy (single or multiple agents) • If metastases are limited: Surgery, radiation therapy, or radiation therapy with systemic therapy • Supportive care
Performance status of 2	<p>The 3 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Single-agent systemic therapy • Supportive care
Performance status of 3 or 4	<p>The 2 options are:</p> <ul style="list-style-type: none"> • Clinical trial (preferred) • Supportive care

Systemic therapy

If you are healthy enough, systemic therapy may be an option. It may be used alone without other treatments. Sometimes, more than one drug is used because drugs differ in the way they work. Other times, only one drug is used so side effects won't be severe.

Radiation therapy with or without systemic treatment

If the metastases aren't widespread, radiation therapy also may be an option. It may be combined with systemic therapy if you are healthy enough.

Surgery

If the metastases aren't widespread, surgery may be an option. The cancer must be in a confined spot so all of it can be removed.

The goal is to control the growth of cancer and prevent symptoms.

Supportive care

Cancer treatment may be too harmful. In this case, supportive care will be given. It aims to improve your quality of life. It is sometimes called palliative care.

Supportive care includes care for health issues caused by cancer. An example is the use of radiation therapy to relieve pain. Talk with your treatment team to plan the best supportive care for you.

Review

- Recurrent cancer is cancer that comes back after a cancer-free time period. Persistent cancer is cancer that remains in the body after treatment. These cancers are treated alike.
- Locoregional cancers have not spread far from the oropharynx. If surgery is not an option, radiation therapy may be used instead. NCCN experts prefer that a second course of radiation therapy be received within a clinical trial. Systemic therapy may be a part of treatment if you are healthy enough.
- Metastatic cancers have spread far from the oropharynx. NCCN experts prefer a clinical trial among all treatment options. Systemic therapy is often used to treat metastases. If the metastases are within a confined space, local treatment with surgery or radiation therapy with or without systemic therapy are options. If your health is poor, supportive care may be received.



I was his advocate at the hospital when he had no voice. I was strong for him when he wasn't feeling strong. I was there to love him and support him however I could."

– Julie

Caregiver and friend

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Making treatment decisions

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WHAT
SHOULD
I DO



It's important to be comfortable with the cancer treatment you choose. This choice starts with having an open and honest conversation with your doctors.

It's your choice

In shared decision-making, you and your doctors share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your doctor.

Treatment decisions are very personal. What is important to you may not be important to someone else.

Some things that may play a role in your decisions:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments like surgery or chemotherapy
- Your feelings about pain or side effects such as nausea and vomiting
- Cost of treatment, travel to treatment centers, and time away from work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from treatment. Discuss openly the risks and benefits of specific treatments and procedures. Weigh options and share concerns with your doctor. If you take the time to build a relationship with your doctor, it

will help you feel supported when considering options and making treatment decisions.

Second opinion

It is normal to want to start treatment as soon as possible. While cancer can't be ignored, there is time to have another doctor review your test results and suggest a treatment plan. This is called getting a second opinion, and it's a normal part of cancer care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see doctors who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the doctor you will see for your second opinion.

Support groups

Many people diagnosed with cancer find support groups to be helpful. Support groups often include people at different stages of treatment. Some people may be newly diagnosed, while others may be finished with treatment. If your hospital or community doesn't have support groups for people with cancer, check out the websites listed in this book.

Questions to ask your doctors

Possible questions to ask your doctors are listed on the following pages. Feel free to use these questions or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment.

Questions to ask about testing and staging

1. What tests will I have?
2. When will I have a biopsy? Will I have more than one? What are the risks?
3. How do I prepare for testing?
4. What if I am pregnant?
5. Where do I go to get tested? How long will the tests take and will any test hurt?
6. Should I bring someone with me? Should I bring a list of my medications?
7. How soon will I know the results and who will explain them to me?
8. Would you give me a copy of the pathology report and other test results?
9. What type of head and neck cancer do I have? Where did it start in my body?
10. What is the cancer stage? Does this stage mean the cancer has spread far?
11. Is this a fast- or slow-growing cancer?
12. Can this cancer be cured? If not, how well can treatment stop the cancer from growing?
13. Who will talk with me about the next steps? When?

Questions to ask about treatment options

1. What are my treatment options? Are you suggesting options other than what NCCN recommends? If yes, why?
2. Do your suggested options include clinical trials? Please explain why.
3. What will happen if I do nothing?
4. How do my age, overall health, and other factors affect my options? What if I am pregnant or planing to get pregnant?
5. Does any option offer a cure or long-term cancer control? Are my chances any better for one option than another? Less time-consuming? Less expensive?
6. How do you know if treatment is working? How will I know if treatment is working?
7. What are my options if treatment stops working?
8. What are the possible complications? What are the short- and long-term side effects of treatment?
9. How will treatment affect my looks, speech, chewing, and swallowing? Will my sense of smell or taste change?
10. What can be done to prevent or relieve the side effects of treatment?
11. What supportive care services are available to me during and after treatment?
12. Can I stop treatment at any time? What will happen if I stop treatment?

Questions to ask about clinical trials

1. Are there clinical trials for my type of cancer?
2. What are the treatments used in the clinical trial?
3. What does the treatment do?
4. Has the treatment been used before? Has it been used for other types of cancer?
5. What are the risks and benefits of this treatment?
6. What side effects should I expect? How will the side effects be controlled?
7. How long will I be in the clinical trial?
8. Will I be able to get other treatment if this doesn't work?
9. How will you know the treatment is working?
10. Will the clinical trial cost me anything? If so, how much?

Questions to ask about getting treated

1. Will I have to go to the hospital or elsewhere? How often? How long is each visit?
2. What do I need to think about if I will travel for treatment?
3. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?
4. How do I prepare for treatment? Do I have to stop taking any of my medicines? Are there foods I will have to avoid?
5. Should I bring someone with me when I get treated?
6. Will the treatment hurt?
7. How much will the treatment cost me? What does my insurance cover?
8. Will I miss work or school? Will I be able to drive?
9. Is home care after treatment needed? If yes, what type?
10. How soon will I be able to manage my own health?
11. When will I be able to return to my normal activities?

Websites

American Cancer Society

cancer.org/cancer/oral-cavity-and-oropharyngeal-cancer.html

Head and Neck Cancer Alliance (HNCA)

headandneck.org

National Cancer Institute (NCI)

cancer.gov/types/head-and-neck

NCCN for Patients®

nccn.org/patients

Oral Cancer Foundation

oralcancerfoundation.org

Smokefree.gov

smokefree.gov

Support for People with Oral and Head and Neck Cancer (SPOHNC)

spohnc.org

THANC – The THANC Foundation

thancfoundation.org

Thyroid Care Collaborative

thyroidccc.org



Words to know

5-FU

5-fluorouracil

adjuvant treatment

Treatment that is given to lower the chances of the cancer returning.

AJCC

American Joint Committee on Cancer

anesthesia

A drug-induced loss of feeling in the body for pain relief.

biopsy

A procedure that removes fluid or tissue samples to be tested for a disease.

cancer stage

A rating of the outlook of a cancer based on its growth and spread.

carcinoma

A cancer of cells that line the inner or outer surfaces of the body.

chemotherapy

Cancer drugs that stop the cell life cycle so cells don't increase in number.

clinical stage

The rating of the extent of cancer before treatment is started.

clinical trial

A type of research that assesses health tests or treatments.

computed tomography (CT)

A test that uses x-rays from many angles to make a picture of the insides of the body.

definitive radiation therapy

Treatment with radiation used to try to cure the cancer.

dental exam

A study of your teeth and gums.

distress

An unpleasant experience of a mental, physical, social, or spiritual nature.

EBRT

External beam radiation therapy

ECOG

Eastern Cooperative Oncology Group

endoscope

A device that is passed through a natural opening to do work inside the body.

extranodal extension

The growth of cancer from within a lymph node to outside the lymph node.

FDG

fluorodeoxyglucose

fine-needle aspiration (FNA)

A procedure that removes tissue samples with a very thin needle.

HPV

Human papillomavirus

hypopharynx

The lowest part of the throat.

IHC

immunohistochemistry

imaging

A test that makes pictures (images) of the insides of the body.

IMRT

intensity-modulated radiation therapy

immunotherapy

A treatment with drugs that help the body find and destroy cancer cells.

induction therapy

The first treatment, consisting of cell-killing drugs, that is given to greatly reduce the extent of cancer.

ISH

in situ hybridization

lymph

A clear fluid containing white blood cells.

lymph node

A small, bean-shaped disease-fighting structure.

magnetic resonance imaging (MRI)

A test that uses radio waves and powerful magnets to make pictures of the insides of the body.

medical history

A report of all your health events and medications.

medical oncologist

A doctor who's an expert in cancer drugs.

metastasis

The spread of cancer from the first tumor to a new site.

nasopharynx

The part of the throat that is behind the nose.

neck dissection

An operation that removes lymph nodes and other tissue in the neck area.

oropharynx

The middle part of the throat.

Panorex x-ray

A test that makes a picture of the insides of the entire mouth.

pathologic stage

A rating of the extent of cancer based on tests given after treatment.

pathologist

A doctor who's an expert in testing cells and tissue to find disease.

PCR

Polymerase chain reaction

PEG

percutaneous endoscopic gastrostomy

performance status

A rating of one's ability to do daily activities.

physical exam

A study of the body by a health expert for signs of disease.

positron emission tomography (PET)

A test that uses radioactive material to see the shape and function of body parts.

primary tumor

The first mass of cancer cells.

prognosis

The likely course and outcome of a disease based on tests.

radiation therapy

A treatment that uses high-energy rays.

radiologist

A doctor who is an expert in reading imaging tests.

recurrence

The return of cancer after a cancer-free period.

registered dietician

A nationally-credentialed expert in food and diet.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

supportive care

Health care that includes symptom relief but not cancer treatment. Also called palliative care.

surgery

An operation to remove or repair a part of the body.

surgical margin

The normal-looking tissue around a tumor that was removed during an operation.

systemic therapy

A type of treatment that works throughout the body.

targeted therapy

A drug treatment that impedes the growth process specific to cancer cells.

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Head and Neck Cancer. It was adapted, reviewed, and published with help from the following people:

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