



NCCN  
GUIDELINES  
FOR PATIENTS®

2018

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# Oral Cancers

NCCN HEAD AND NECK CANCERS SERIES

Presented with support from:



NATIONAL COMPREHENSIVE CANCER NETWORK  
**FOUNDATION**  
Guiding Treatment. Changing Lives.



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## LEARNING that you have cancer can be overwhelming.

The goal of this book is to help you get the best care. It explains which cancer tests and treatments are recommended by experts in oral cancers.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 leading cancer centers. Experts from NCCN have written treatment guidelines for doctors who treat oral cancers. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on the treatment of oral cancers. Key points of the book are summarized in the related [NCCN Quick Guide™](#). NCCN also offers patient books on throat cancer, esophageal cancer, lung cancer, and many other cancer types. Visit [NCCN.org/patients](https://www.nccn.org/patients) for the full library of patient books, summaries, and other resources.

# About



These patient guidelines for cancer care are produced by the National Comprehensive Cancer Network® (NCCN®).

The mission of NCCN is to improve cancer care so people can live better lives. At the core of NCCN are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN Guidelines® contain information to help health care workers plan the best cancer care. They list options for cancer care that are most likely to have the best results. The NCCN Guidelines for Patients® present the information from the NCCN Guidelines in an easy-to-learn format.

Panels of experts create the NCCN Guidelines. Most of the experts are from NCCN Member Institutions. Their areas of expertise are diverse. Many panels also include a patient advocate. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors.

For more information about the NCCN Guidelines, visit [NCCN.org/clinical.asp](http://NCCN.org/clinical.asp).

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NCCN Foundation was founded by NCCN to raise funds for patient education based on the NCCN Guidelines. NCCN Foundation offers guidance to people with cancer and their caregivers at every step of their cancer journey. This is done by sharing key information from leading cancer experts. This information can be found in a library of NCCN Guidelines for Patients® and other patient education resources. NCCN Foundation is also committed to advancing cancer treatment by funding the nation's promising doctors at the center of cancer research, education, and progress of cancer therapies.

For more information about NCCN Foundation, visit [NCCNFoundation.org](http://NCCNFoundation.org).

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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](http://headandneck.org)



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

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](http://spohnc.org)



### The Oral Cancer Foundation

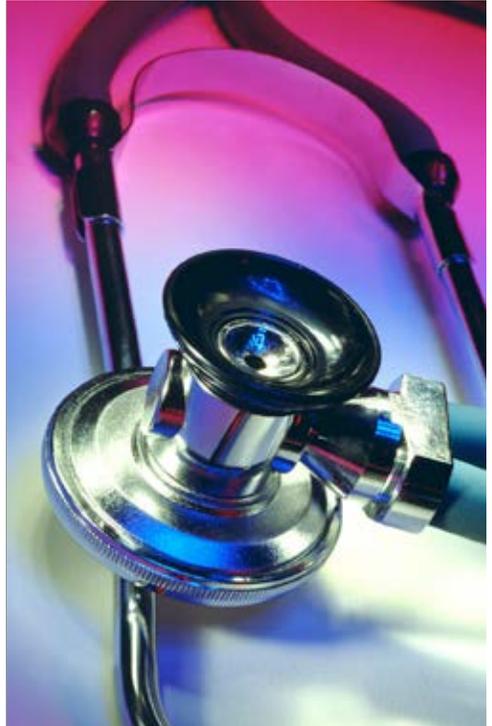
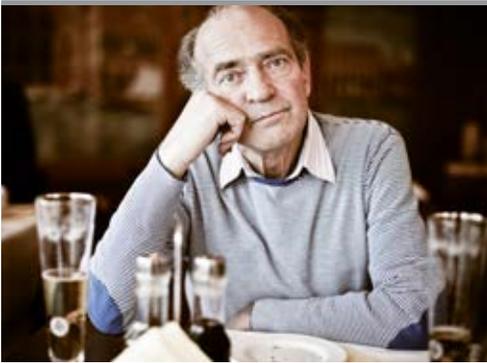
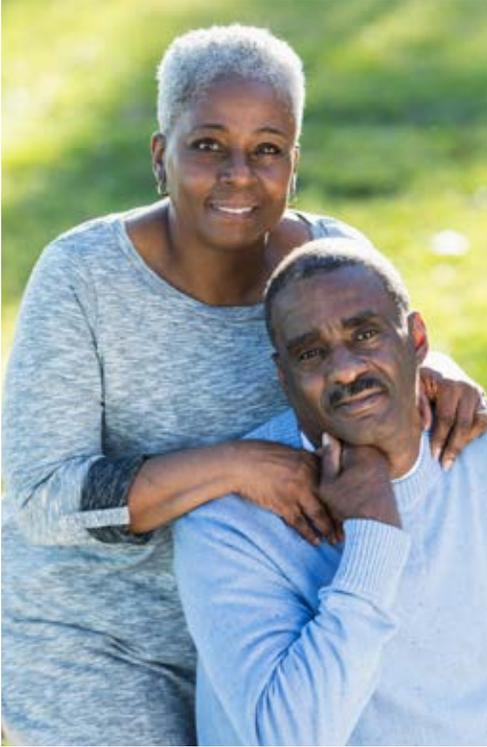
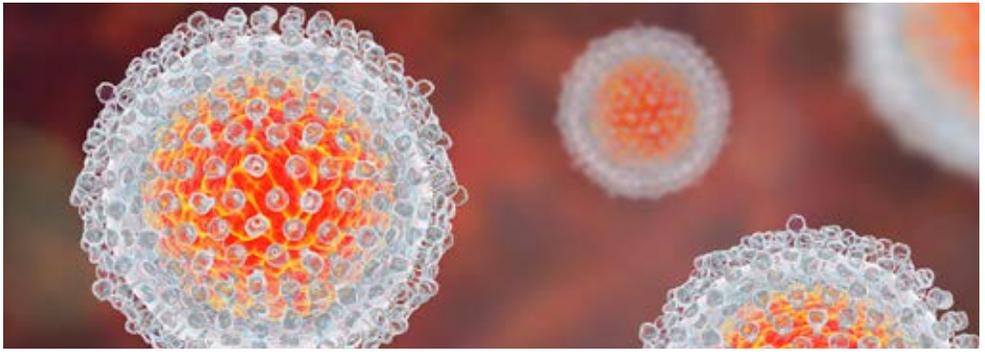
The foundation is pleased to support and endorse the NCCN Guidelines for Patients. These guidelines provide another tool for patients to make sound science-based decisions from as they navigate the treatment options and journey through the cancer experience. As an organization that works to provide vetted 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](http://oralcancerfoundation.org)

## With generous support from

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### Who should read this book?

Treatment for oral cancers is the focus of this book. Patients and those who support them—caregivers, family, and friends—may find this book helpful. It is a good starting point to learn what your options may be.

### Are the book chapters in a certain order?

Early chapters explain concepts that are repeated in later chapters. Starting with **Part 1** may be helpful. It explains what oral cancers are and how they are staged.

**Part 2** lists what health care is needed before treatment. Some types of health care help your doctors plan treatment. Other health care is for issues besides cancer treatment.

Not everyone receives the same treatment. In **Parts 3–5**, treatment options are listed based on the cancer stage. Tips for making treatment decisions are presented in **Part 6**.

### Does this book include all options?

This book includes information for many people. Your treatment team can point out what applies to you. They can also give you more information. While reading, make a list of questions to ask your doctors.

The treatment options are based on science and the experience of NCCN experts. However, their recommendations may not be right for you.

Your doctors may suggest other options based on your health and other factors. If other options are given, ask your treatment team questions.

### Help! What do the words mean?

In this book, many medical words are included. These are words that your treatment team may say to you. Most of these words may be new to you. It may be a lot to learn.

Don't be discouraged as you read. Keep reading and review the information. Ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the *Dictionary*. Acronyms are also defined when first used and in the *Glossary*. Acronyms are short words formed from the first letters of several words. One example is DNA for **d**eoxyribonucleic acid.

# 1

## Oral cancer basics

- 8 Lips and mouth
- 10 A disease of cells
- 11 Cancer's threat
- 12 Cancer stages
- 12 Treatment types
- 14 Review



You've learned that you have oral cancer. It's common to feel shocked and confused. This chapter reviews some basics that may help you learn about oral cancer.

## Lips and mouth

Before learning about oral cancers, it is helpful to know about the lips and mouth. These parts of the body are needed for talking and eating. The lips keep food in the mouth and help to pronounce words. The mouth starts to break down food for the body to digest. It also helps you say words.

### Lips

The outer (or dry) lips are like your skin. So, cancers of the outer lips are treated as skin cancers. These cancers are not covered in this book.

The inner (or wet) lips are like the insides of your cheeks. **See Figure 1.** Cancers of the inner lips are treated as oral cancers. Treatment for these cancers is covered in this book.

### Mouth

Oral cancers include cancers of the mouth. They do not include bone cancers of the jaw. Oral cancers often occur in these parts of the mouth:

- ▶ The **buccal mucosa** is the inside of the cheeks.
- ▶ The **floor of the mouth** is under your tongue between your teeth.
- ▶ The **anterior tongue** is the first two-thirds of your tongue.
- ▶ The **alveolar ridge** is the gums around the base of your teeth.
- ▶ The **retromolar trigone** is the gums behind your wisdom teeth.
- ▶ The **hard palate** is the roof of your mouth.

### Lymph nodes

Throughout your body—including your mouth—is a clear fluid called lymph. Lymph gives cells food and water. It also contains germ-fighting blood cells. Lymph drains from tissue into vessels that transport it to the bloodstream. **See Figure 2.** As lymph travels, it passes through small structures called lymph nodes. Lymph nodes remove germs from lymph.



*I still have challenges as a result of the treatments, but every day that I have to endure these reminders is another day that I get to appreciate still being here, experiencing the joy of being with my family.*

– Tony

*10-year cancer survivor*

*Stage IV tongue and tonsil cancer*

### Figure 1 Lips and mouth

Oral cancers occur in the inner lips, the anterior tongue, inner cheeks, roof of the mouth, floor of the mouth (not shown), and gums.

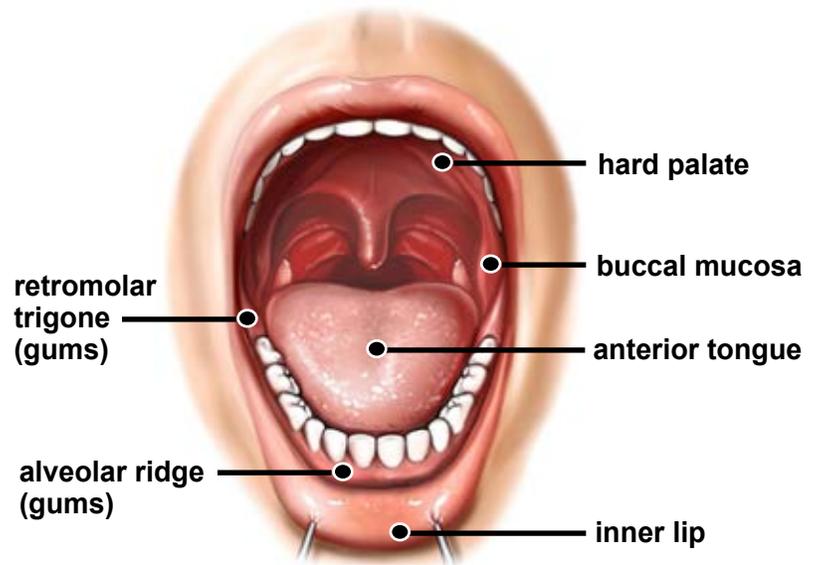


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### Figure 2 Lymph nodes

Throughout your body is a clear fluid called lymph. It drains from tissues into vessels that carry it back to the bloodstream. As lymph travels, it passes through lymph nodes. Lymph nodes remove germs from lymph. Lymph vessels and nodes are depicted in green in the figure.

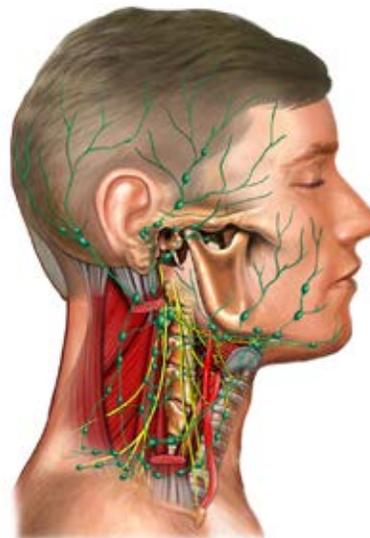


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## A disease of cells

Your body is made of trillions of cells. Cancer is a disease of cells. Each type of cancer is named after the cells from which it formed.

Almost all oral cancers are carcinomas. Carcinomas are cancers of cells that line the inner or outer surfaces of the body. There is more than one type of oral carcinoma. The most common type is squamous cell carcinoma. Squamous cells cover the lips and other areas of the mouth.

### Mutations

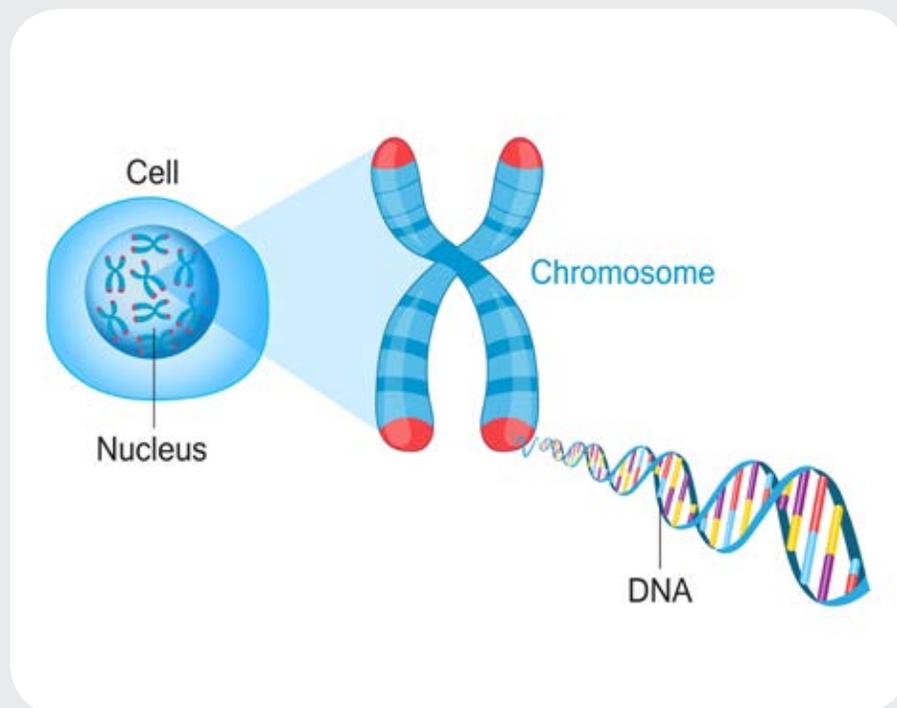
Cells have a control center called the nucleus. Within the nucleus are chromosomes. Chromosomes are long strands of DNA (deoxyribonucleic acid) that

are tightly wrapped around proteins. **See Figure 3.** Within DNA are coded instructions for building new cells and controlling how cells behave. These instructions are called genes.

There can be abnormal changes in genes called mutations. Some types of mutations that are linked to cancer are present in all cells. Other mutations are present only in cancer cells. Mutations cause cancer cells to behave unlike normal cells. They sometimes cause cancer cells to look very different from normal cells.

### Figure 3 Genetic material in cells

**Most human cells contain a plan called the “blueprint of life.” It is a plan for how our bodies are made and work. It is found inside of chromosomes. Chromosomes are long strands of DNA that are tightly wrapped around proteins. Genes are small pieces of DNA. Humans have about 20,000 to 25,000 genes.**



## Cancer's threat

When needed, normal cells grow and then divide to form new cells. When old or damaged, they die as shown in **Figure 4**. Normal cells also stay in place. Cancer cells don't behave like normal cells. Cancer cells differ from normal cells in three key ways.

### Mass of cells

Cancer cells make new cells that aren't needed. They don't die quickly when old or damaged. Over time, cancer cells form a mass called the primary tumor.

### Invasion

Cancer cells can grow into surrounding tissues. If not treated, the primary tumor can grow beyond the

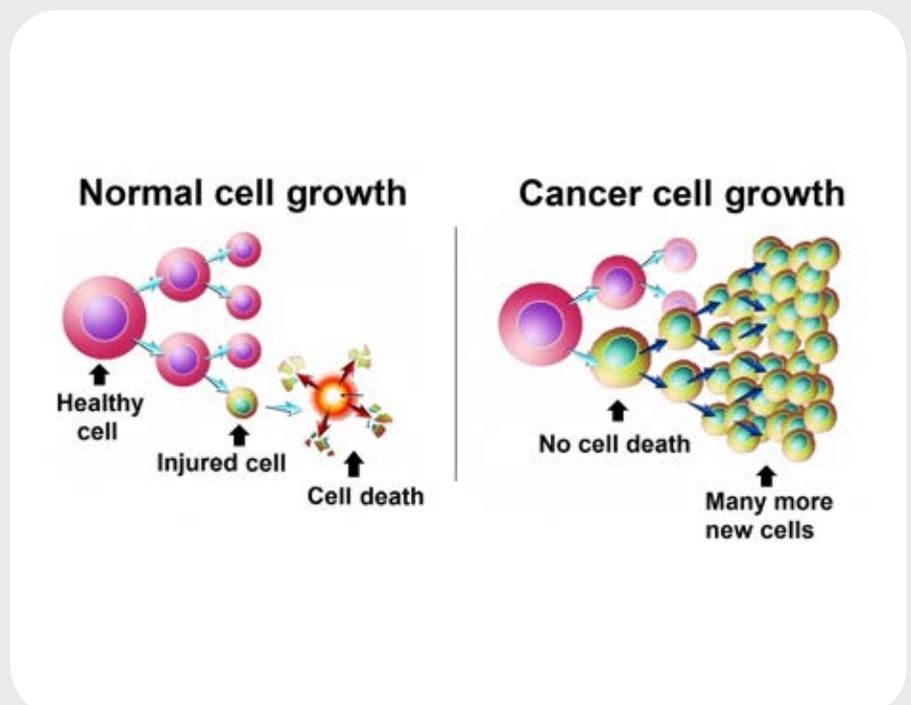
surface of the mouth into deeper tissue. Examples include growth into the jawbone, skin, or sinuses. Invasion can cause pain. It can also make it hard to talk, chew, or taste.

### Metastasis

Third, unlike normal cells, cancer cells can leave the lips and mouth. This process is called metastasis. In this process, cancer cells break away from the tumor and merge with blood or lymph. Then, the cancer cells travel through blood or lymph vessels to other sites. Once in other sites, cancer cells may form secondary tumors. Over time, major health problems can occur.

**Figure 4**  
Normal cells vs. cancer cells

Normal cells increase in number when they are needed and die when old or damaged. In contrast, cancer cells quickly make new cells and live longer because of mutations in genes.



## Cancer stages

A cancer stage is a rating of the cancer based on test results. Your doctor uses 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.

Cancer staging is often done twice. The rating before any treatment is called the clinical stage. The rating after surgery is called the pathologic stage.

### Staging system

The AJCC (**A**merican **J**oint **C**ommittee on **C**ancer) staging system is used to stage oral 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. There are 6 main scores. TX means the primary tumor could not be found. Tis means the tumor is only within the top layer of tissue. T1 through T3 describe the size of the tumor. T4 is based on either size or growth into nearby structures. The more serious the growth the higher the T score.

#### N score

The N score describes the cancer status of nearby lymph nodes. There are 5 main scores. NX means the nodes could not be assessed. N0 means the nodes are cancer-free. N1 through N3 is based on 1) number of nodes with cancer; 2) cancer on one or both sides of the neck; 3) nodal size; and 4) cancer growth through the outer wall of the node. The more serious the growth the higher the N score.

#### M score

The M score tells if the cancer has spread to body parts distant from the mouth and neck. M0 means there are no distant metastases. M1 means one or more distant metastases are present. The lungs

are the most common place to which oral cancers spread. They also can spread to the bone and liver.

### Numbered stages

The TNM scores are combined to assign the cancer a stage. The stages range from stage 0 to stage 4. Stage 4 is further grouped by the letters A through C. Doctors write these stages as—stage 0, stage I, stage II, stage III, stage IVA, stage IVB, and stage IVC.

If the cancer recurs or worsens, the stage stays the same. An example is a stage III cancer that recurs with metastatic disease. It is not now stage IVC. It remains stage III.

The numbered stages are very alike across cancers, but the outcomes differ. For oral cancer, many stages including IVA and IVB are treated with the goal of curing it. For stage IVC, the goal of treatment is to control the growth of the cancer.

## Treatment types

This section briefly describes the treatments used for oral cancers. Not everyone receives the same treatment. Your doctor will tailor treatment to you based on tests described in Part 2. Treatment options based on the cancer stage are discussed in Parts 3 through 5.

### Local therapy

Local therapy treats cancer in a limited region. It cannot fully treat cancer that is widespread. Local therapies for oral cancers include surgery and radiation therapy.

### Surgery

Surgery is a treatment that removes tumors or entire organs with cancer. It is a very common treatment for oral cancers.

The method used depends on where and how much the cancer has grown. Most often, surgeons remove oral cancers through a cut into tissues. The cutting device may be a scalpel, cautery device, or laser beam.

Some small oral cancers may be removed through the open mouth. Lasers or a machine (“robot”) may be used to remove the cancer. A surgeon with the proper training and experience should perform these methods.

### Radiation therapy

Radiation therapy most often uses high-energy x-rays to treat oral cancer. The x-rays damage DNA in cancer cells. This either kills the cancer cells or stops new cancer cells from being made.

For oral cancers, the most common radiation method is EBRT (**e**xternal **b**eam **r**adiation **t**herapy). A large machine makes the high energy x-rays used for treatment. Conformal techniques are used. These techniques shape the radiation dose to the cancer site to spare healthy tissue. NCCN experts recommend the following techniques:

- ▶ **3D-CRT (three-dimensional conformal radiation therapy)** delivers an x-ray beam that matches the shape of the target.
- ▶ **IMRT (intensity-modulated radiation therapy)** better spares normal tissue during treatment by modifying the beam’s intensity.

### Systemic therapy

Systemic therapy is a cancer treatment for the whole body. It will treat the cancer in your mouth or lips. It will also treat cancer in lymph nodes and distant parts of your body.

For oral cancers, systemic therapy consists of cancer drugs. Many of these drugs are liquids that



## Supportive care

Supportive care aims to improve your quality of life. It includes care for health issues caused by cancer or cancer treatment. Talk with your treatment team to get the best supportive care for you.

All cancer treatments can cause unwanted health issues. Such health issues are called side effects. Side effects depend on many factors. These factors include the treatment type and the person. Some side effects may be harmful to your health. Others may just be unpleasant.

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.

are slowly injected into the body. Some drugs are pills to be swallowed.

### Chemotherapy

Chemotherapy works by stopping the cell life cycle. As a result, cancer cells cannot make new cells. Chemotherapy can also cause cells to destroy themselves. Cisplatin is a commonly used chemotherapy drug for oral cancers. It is sometimes used with radiation therapy to treat oral cancers.

### Targeted therapy

For oral cancers, targeted therapy stops growth signals from a structure on cancer cells called EGFR (epidermal growth factor receptor). The drug, cetuximab, stops EGFR signals and allows immune cells to destroy cancer cells. It is commonly used with radiation therapy to treat oral cancers. Afatinib may also help treat oral cancers by stopping EGFR signals. However, more research is needed.

### Immunotherapy

T cells are a type of immune cell that can kill cancer cells. They are unable to attack cancer cells that have a protein called PD-L1. Pembrolizumab and nivolumab block PD-L1 and allow T cells to attack cancer cells.

### Clinical trials

One of your treatment options may be to join a clinical trial. Joining a clinical trial is strongly supported. NCCN believes that you will receive the best management in a clinical trial.

A clinical trial is a type of research that studies a test or treatment in people. It gives people access to health care that otherwise can't usually be received. Ask your treatment team if there is an open clinical trial that you can join.

## Review

- Oral cancers include cancers of the inner lips and mouth.
- The most common type of oral cancer is squamous cell carcinoma. Squamous cells cover the lips and other areas of the mouth.
- Cancer cells form a tumor since they don't grow and die as normal cells do.
- Oral cancers can spread through lymph or blood to other body parts.
- Most oral cancers are treated with surgery. But, you may get other treatments like radiation or chemotherapy.
- Clinical trials give people access to new tests and treatments that they otherwise wouldn't receive.

# 2

## Treatment planning

16 Medical history

16 Physical exam

17 Distress screening

17 Smoking treatment

18 Dental exam

18 Prosthodontic exam

19 Imaging

20 Preanesthesia exam

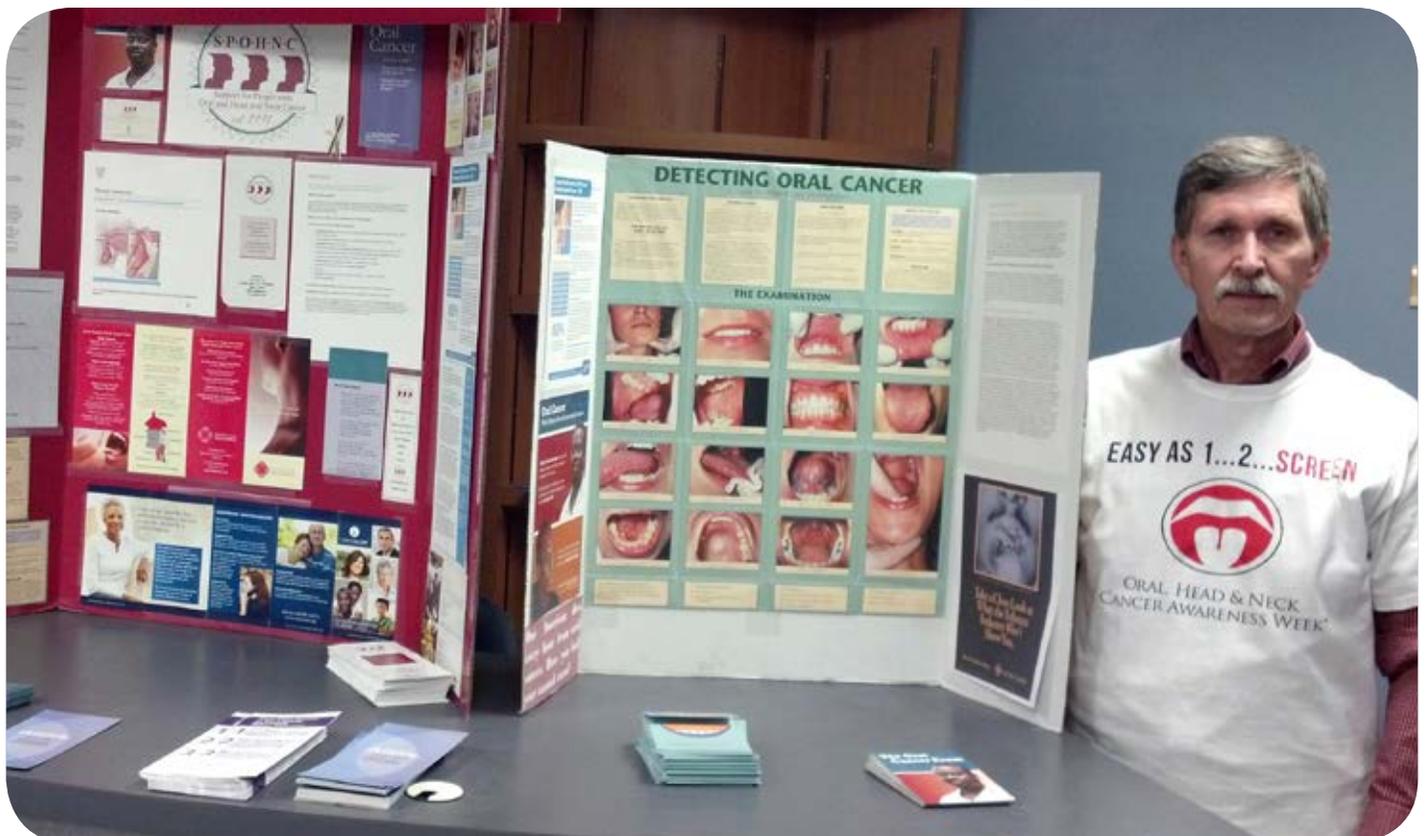
20 Endoscopic exam

21 Biopsy

21 Nutrition assessment

22 Speech and swallowing exam

22 Review



Not all oral cancers are the same. Your cancer doctor will want to learn all about the cancer you have. This chapter describes the tests used to learn about oral cancer. It also describes care for health issues related to the cancer or its treatment.

Doctors plan treatment using many sources of information. These sources include the health care listed in [Guide 1](#). Another source is you. Tell your doctor your concerns and goals for treatment. Together, you can share the decision-making process. Read Part 6 to learn more about making treatment decisions.

## Medical history

Your doctor will ask about any health problems and their treatment during your lifetime. Be prepared to tell what illnesses and injuries you have had. You will also be asked about health conditions and symptoms. It may help to bring a list of old and new medicines to your doctor's office.

Your doctor will ask if you have ever smoked. Tell your doctor if you are a current or past smoker. You'll also be asked how much you've smoked in your lifetime. Smoking is often measured by packs per day.

Some cancers and other health problems can run in families. Thus, your doctor 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.

## 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.

To start, your basic body functions will be measured. These functions include your temperature, blood pressure, and pulse and breathing rate. Your weight will also be checked.

Your doctor will listen to your lungs, heart, and gut. He or she will also assess your eyes, skin, nose, ears, and mouth. Parts of your body will be felt. Your doctor will note the size of organs and if they feel soft or hard. Tell your doctor if you feel pain when touched.

## Guide 1. Health care before treatment

### Tests and services

Medical history

Physical exam

Distress screening

Smoking treatment if needed

Dental exam and if needed, prosthodontic exam

Panorex x-ray if needed

Mouth and neck CT, MRI, or both if needed

Chest CT if needed

FDG PET/CT for stage III or IV is an option

Preanesthesia exam if needed

Endoscopy if needed

Biopsy

Nutrition assessment if needed

Speech or swallowing exam if needed

## Head and neck exam

An exam of your head and neck is key to planning treatment. Your doctor will carefully inspect your lips, mouth, nose, and ears. He or she will feel under your jaw and along your neck for lumps. He or she will also touch the insides of your mouth with gloved fingers.

To look deep inside, your doctor may use a device. One type of device is a mouth mirror like what your dentist uses. Sometimes, doctors use a fiber-optic scope that is passed through the mouth or nose.

## 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, and so forth. 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. Serious or not, 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. Read the [NCCN Guidelines for Patients®: Distress](#) to learn more.



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

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community resources, such as support groups and wellness centers.

## Smoking treatment

If you smoke or chew tobacco, it is important to quit. Both are causes of oral and other 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 doctor about counseling and drugs to help you quit.



We never expected anything like this. It was very hard to get over the “Why us?” questions. But, you jump in and just do. You learn a lot about yourself and the real inner strength you can pull out when needed.

– Connie  
Cancer survivor  
Head and neck cancer

## Dental exam

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 will also be done. Cavities will be fixed. Unhealthy teeth will be removed to prevent problems during 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. He or she will also tell you how to prevent or stop such problems.

## Prosthodontic exam

For some oral cancers, treatment can affect the look and function of the mouth. For example, you may have problems talking or eating after cancer treatment. So, your treatment team may include a prosthodontist. This dentist is an expert in restoring parts of the mouth.

Before cancer treatment, you will meet with your prosthodontist. He or she will make a rehabilitation plan based on the cancer, its treatment, and your goals. Use of a human-made body part (prosthesis) may be part of this plan. A custom-made prosthesis may require a few dental visits before cancer treatment.



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

6-year cancer survivor

Tongue and neck cancer

## Imaging

Imaging makes pictures of the insides of your body. It is used to detect cancer in deep tissue, lymph nodes, or distant body parts. Some imaging also reveals some features of a tumor and its cells.

A radiologist is a doctor who's an expert in reading images. He or she will convey the test results to your doctor.

Some imaging tests use contrast. It makes the images easier to read. Tell your doctor if you've had problems with contrast in the past. Also, allergies to shellfish may mean you'll be allergic to contrast.

### 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.

### CT scan

CT (**computed tomography**) makes a more detailed image than a plain x-ray. It takes many pictures of your body from different angles using x-rays. See Figure 5. A computer then combines the pictures to make a 3-D (**three-dimensional**) image.

### Dental CT

Dental CT may be done instead of a Panorex x-ray. It is often used to assess cancer growth into the jaw. No contrast is needed.

### Mouth and neck CT

Your doctor may want to see if the cancer has spread. CT can be used to look for cancer in nearby lymph nodes. Contrast is needed.

### 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

### Figure 5 CT machine

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



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a high risk for lung cancer. Contrast may or may not be used.

**MRI**

MRI (magnetic resonance imaging) makes 3-D images like CT. Unlike CT, images are made using a magnetic field and radio waves. MRI shows more details of soft tissue than CT does.

**Mouth and neck MRI**

MRI may be done if CT is not an option. Sometimes, it is done in addition to CT. It may be preferred over CT for soft tissue and nerves. Contrast is needed.

**FDG PET/CT**

Sometimes CT is combined with PET (positron emission tomography). 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.

PET/CT with an FDG (fluorodeoxyglucose) radiotracer is an option for advanced oral cancers. It is used to help define the primary tumor. It is also used to look for cancer in nodes or distant body parts. It may show cancer that was not seen with other imaging.

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**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. He or she may review your medical records, ask you questions, and do a physical exam. Sometimes, tests are ordered.

**Endoscopic exam**

For some oral cancers, an endoscopic exam may be done. An endoscope is a hand-held device used to see inside your body. Your doctor will guide its thin, tube-shaped part through your 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.

## Biopsy

A biopsy is a procedure that removes tissue or fluid samples for lab testing. Doctors use imaging results to decide what tissue to biopsy. In a lab, a pathologist will study the samples with a microscope. He or she will confirm if cancer is present.

There is more than one type of biopsy. The type of biopsy that will be used partly depends on where the tumor is. Your doctor may use a scalpel to remove part or all of the tumor. A punch biopsy removes tissue with a circle-shaped blade. An FNA (fine-needle aspiration) removes a small group of cells with a needle. FNA is the preferred method for a neck lump that might be cancer. Your doctor may use imaging to obtain a large enough sample.

All lab results are included in a pathology report. This report will be sent to your doctor. Ask him or her for a copy. Your doctor will review the results with you. Take notes and ask questions.

## Nutrition assessment

Some oral 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. He or she will ask about what you eat and drink. Based on your answers, he or she will make a nutritional plan for you.

You may be assessed for a feeding tube. There are different types. A nasogastric tube is placed through the nose, down the throat, and into the stomach. A PEG (percutaneous endoscopic gastrostomy) tube is placed through the skin directly into the stomach.



## Team work

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

- ✓ Dentist
- ✓ Head and neck surgeon
- ✓ Radiation oncologist
- ✓ Medical oncologist
- ✓ Nurse
- ✓ Pathologist
- ✓ Radiologist
- ✓ Plastic surgeon
- ✓ Speech therapist
- ✓ Physical therapist
- ✓ Registered dietician
- ✓ Case manager
- ✓ Mental health professional
- ✓ Supportive care specialist

## Speech and swallowing exam

Oral cancer or its treatment can cause problems with speech and 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.

Your 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 that may occur before and during cancer treatment.



I learned to eat again. It seems to be almost normal now. The saliva problem is manageable. I carry water everywhere I go and drink a lot of water when I eat. Generally, I just waited for the healing process to take place and realized some things in life would be different and moved on.

– Chuck

Cancer survivor

Head and neck cancer

## Review

- Your doctor will ask you about any health problems in your lifetime and their treatment.
- Your doctor will study your body to assess your health. He or she will touch parts of your body, including inside your mouth, to see if anything feels abnormal.
- Your doctor can get you help for distress and to quit smoking.
- A dental exam is needed to get you ready for treatment.
- You may meet with a dentist who will help restore the look and function of your mouth.
- Imaging makes a picture of the insides of your body that doctors use for cancer staging.
- An anesthesiologist may need to assess if anesthesia is safe for you.
- For advanced cancers, a hand-held viewing device may be used for cancer staging.
- Tissue samples must be removed and tested to confirm the presence of cancer.
- Oral cancer and its treatment may cause problems with eating and talking. Experts in diet, speech, and swallowing can help.

# 3

## Treatment guide: Stages I and II

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This chapter presents the treatment options for early oral cancers. It also reviews key parts of follow-up care. Discuss with your doctor which options are right for you.

## Treatment

For early cancers, surgery and radiation therapy are treatment options. Surgery is usually preferred, but radiation may be better for some people. Ask your doctor about the pros and cons of each option. Also, ask about ways to restore the function and look of your mouth after treatment.

### Surgery

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.

### Sentinel lymph node biopsy

Early oral cancers rarely spread to lymph nodes in the neck. When there's a greater chance of spread, a sentinel lymph node biopsy may be done. Sentinel lymph nodes are the first nodes to which oral cancer spreads. A surgeon with the proper training and experience should perform this biopsy.

### Neck dissection

For mouth cancers, lymph nodes from several areas in the neck may be removed. Removal of these lymph nodes is called a neck dissection. The removed nodes will be tested for cancer. If cancer is found, more nodes may be removed.

Your surgeon may perform a neck dissection based on:

- Thickness of the tumor,
- Location of the tumor, or
- Results of a sentinel lymph node biopsy.

Thicker mouth tumors are more likely to have spread to neck lymph nodes. For thick tumors, a neck dissection may be done on the same side of your body as the tumor.

Some mouth tumors spread to lymph nodes on both sides of the neck. Examples include tumors near the middle of the mouth or the tip of the tongue. In these cases, a neck dissection may be done on both sides of your neck.

A neck dissection will be done if cancer is found in sentinel nodes. Sometimes, the sentinel nodes can't be found during a biopsy. In this case, your doctor will perform a neck dissection.

### Adjuvant therapy after surgery

More treatment may be given to treat any cancer that remains. Treatment for this purpose is called adjuvant therapy. It helps stop the cancer from coming back. Radiation is commonly used for adjuvant therapy. Chemotherapy may be added.

The need for adjuvant therapy is mainly based on adverse features. [See Guide 2](#). Cancer in the surgical margins is an adverse feature. Cancer growth through the outer wall of lymph nodes is another adverse feature. This is called extranodal extension. Other adverse features include high pathologic T or N stages, or growth to nerves or vessels.

## Guide 2. Adjuvant treatment

### Inner lip cancers

Adverse features	What are the options?
None	<ul style="list-style-type: none"> <li>• Start follow-up care</li> </ul>
Cancer is in the surgical margin	<ul style="list-style-type: none"> <li>• Surgery</li> <li>• Radiation therapy</li> </ul>
Cancer growth to nerves or vessels	<ul style="list-style-type: none"> <li>• Radiation therapy</li> </ul>

### Mouth cancers (eg, gums, tongue, inner cheek)

Adverse features	What are the options?
None	<ul style="list-style-type: none"> <li>• Start follow-up care</li> </ul>
One node with cancer + no other adverse features	<ul style="list-style-type: none"> <li>• Start follow-up care</li> <li>• Radiation therapy</li> </ul>
Cancer growth through a lymph node's outer wall	<ul style="list-style-type: none"> <li>• Radiation therapy + systemic therapy</li> </ul>
Cancer is in the surgical margin	<ul style="list-style-type: none"> <li>• Surgery</li> <li>• Radiation therapy</li> <li>• Radiation therapy + systemic therapy</li> </ul>
Other adverse features	<ul style="list-style-type: none"> <li>• Radiation therapy</li> <li>• Radiation therapy + systemic therapy</li> </ul>

### Radiation therapy

Radiation therapy may be used as the main treatment at times. When used for this purpose, it is called definitive radiation therapy. Stronger doses of radiation therapy will be given.

Some oral cancers get more radiation called a boost. The boost is given through a radioactive implant placed next to cancer cells. This method is called brachytherapy. Radiation oncologists with the proper training and experience should perform this method.

Imaging will be used to check radiation results. FDG PET/CT is often preferred among the imaging methods. Imaging is often done 10 to 12 weeks after the last radiation session. If cancer remains, surgery may be done to remove it.

## Follow-up care

Follow-up care is important for your long-term health. It is started when there are no signs of cancer. Talk with your treatment team to get the best care for you.

You will meet with your doctor often after treatment ends. At these visits, your doctor will perform a medical history and physical exam. Five years after treatment, you may see your doctor only once a year.

Imaging may be done to assess for cancer. It is useful when a part of your neck or head can't be clearly seen on exam. It may be done if signs or symptoms of cancer appear. People at high risk for lung cancer should enroll in a screening program. Read the [NCCN Guidelines for Patients: Lung Cancer Screening](#) for more information.

Your doctors will also assess for late side effects of treatment. An example is a drop in levels of thyroid hormones after radiation therapy to the neck.

Likewise, your dentist will help to prevent cavities, jaw problems, and infections.

Follow-up care may involve working with specialists. You may need to work with a speech-language pathologist to improve your speech or swallowing. A dietician can help you get good nutrition. Mental health providers can help you quit smoking and limit alcohol.



Doctors can fix the broken body,  
but not always the heart. Being a  
cancer survivor, I have realized that  
cancer is not always the end. It can  
be a positive beginning.

– Terri

Cancer survivor

Head and neck cancer

## Recurrence

Doctors call the return of cancer a recurrence. Treatment is partly based on where the cancer returns. Your prior treatment is important, too.

Some recurrences can be treated with surgery. Radiation therapy with or without systemic therapy may follow. When surgery is not an option, radiation therapy, systemic therapy, or both may be given. Also, ask your doctor if there is a clinical trial that is right for you.

## Review

- Surgery and radiation therapy are options for early oral cancers. More treatment may follow to help prevent the cancer from coming back.
- Visit your cancer doctor for follow-up care. He or she will assess for any new signs of cancer. Also, tell your doctor about any new or worse symptoms. Health problems from cancer treatments may start during follow-up.
- After cancer treatment, you may need help with talking and eating.
- Early oral cancer may return after a cancer-free period. Tests of the cancer will be used to tailor treatment to you.

# 4

## Treatment guide: Stages III, IVA, and IVB (T1–T4a)

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This chapter presents the treatment options for advanced oral cancers. It also reviews key parts of follow-up care. Discuss with your doctor which options are right for you.

## Treatment

Initial treatment options for advanced cancers are listed in [Guide 3](#). Options are mainly based on whether surgery can be done. If surgery is not an option, the options for stage IVB (T4b) may be right for you. These options are discussed in Part 5.

If surgery can be done, it is the preferred treatment option. Changes in speech and swallowing are often minor due to reconstruction and rehabilitation. Ask your doctor about ways to restore the function and look of your mouth after treatment.

There may be reasons to choose a treatment other than surgery. Radiation therapy may be a better treatment for cancer that covers most of the lip. That's because large lip defects after cancer surgery are hard to fix. For mouth cancers, research on

### Guide 3. Initial treatment for advanced cancers

#### What are the options?

*If surgery is an option:*

- Surgery (preferred)
- Radiation therapy ± systemic therapy for lip cancers only
- Clinical trial

*If surgery is not an option:*

- See options for IVB (T4b) in [Guide 5](#)

treatment options other than surgery is needed. Ask your doctor if there is a clinical trial that is right for you.

### Surgery

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.

### Neck dissection

For many oral cancers, lymph nodes in the neck will be removed. Removal of these lymph nodes is called a neck dissection. Neck dissection is based on the N stage:

- For **N0**, a neck dissection is an option for inner lip cancers. But for mouth cancers, it is advised by NCCN experts.
- For **N1**, **N2a**, **N2b**, and **N3**, a neck dissection on the same side of your body as the tumor is advised. Nodes on the other side of your neck may be removed as needed.
- For **N2c**, a neck dissection of nodes on both sides of your neck is advised.



Hope is as necessary to survival as treatment.

– Will

Cancer survivor

Head and neck cancer

**Adjuvant therapy after surgery**

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

The need for adjuvant therapy is mainly based on adverse features. [See Guide 4](#). Cancer in the surgical margins is an adverse feature. Cancer growth through the outer wall of lymph nodes is

another adverse feature. This is called extranodal extension. Other adverse features include high pathologic T or N stages, growth to nerves or vessels, and 2 or more nodes with cancer.

Radiation is commonly used for adjuvant therapy. Chemotherapy may be given during radiation. This is called concurrent chemoradiation. If cancer is in the surgical margin, a second surgery may be done.

**Guide 4. Adjuvant treatment****Inner lip cancers**

Adverse features	What are the options?
Stage N0 and no adverse features	<ul style="list-style-type: none"> <li>• Start follow-up care</li> </ul>
One node with cancer + no other adverse features	<ul style="list-style-type: none"> <li>• Start follow-up care</li> <li>• Radiation therapy</li> </ul>
Cancer growth through a lymph node's outer wall or cancer is in the surgical margin	<ul style="list-style-type: none"> <li>• Radiation therapy + systemic therapy (preferred)</li> <li>• Surgery</li> <li>• Radiation therapy</li> </ul>
Other adverse features	<ul style="list-style-type: none"> <li>• Radiation therapy</li> <li>• Radiation therapy + systemic therapy</li> </ul>

**Mouth cancers (eg, gums, tongue, inner cheek)**

Adverse features	What are the options?
None	<ul style="list-style-type: none"> <li>• Start follow-up care</li> <li>• Radiation therapy</li> </ul>
Cancer growth through a lymph node's outer wall	<ul style="list-style-type: none"> <li>• Radiation therapy + systemic therapy</li> </ul>
Cancer is in the surgical margin	<ul style="list-style-type: none"> <li>• Radiation therapy + systemic therapy (preferred)</li> <li>• Surgery and if cancer-free margins ± radiation therapy</li> </ul>
Other adverse features	<ul style="list-style-type: none"> <li>• Radiation therapy</li> <li>• Radiation therapy + systemic therapy</li> </ul>

### Radiation therapy

For inner lip cancers, radiation therapy may be used as the main treatment. When used for this purpose, it is called definitive radiation therapy. Stronger doses of radiation therapy will be given.

Some lip cancers get more radiation called a boost. The boost is given through a radioactive implant placed next to cancer cells. This method is called brachytherapy. Radiation oncologists with the proper training and experience should perform this method.

Imaging will be used to check radiation results. FDG PET/CT is often preferred among the imaging methods. Imaging is often done 10 to 12 weeks after the last radiation session. If cancer remains, surgery may be done to remove it.

### Radiation therapy with systemic therapy

For some lip cancers, a third option is getting radiation therapy and systemic therapy at the same time. This treatment is called concurrent chemoradiation. Cisplatin is commonly used.

## Follow-up care

Follow-up care is important for your long-term health. It is started when there are no signs of cancer. Talk with your treatment team to get the best care for you.

You will meet with your doctor often after treatment ends. At these visits, your doctor will perform a medical history and physical exam. Five years after treatment, you may see your doctor only once a year.

Imaging may be done to assess for cancer. It is useful when a part of your neck or head can't be seen on exam. It may be done if signs of cancer appear. People at high risk for lung cancer should enroll in a screening program. Read the NCCN Guidelines for Patients: Lung Cancer Screening for more information.

Your doctors will also assess for late side effects of treatment. An example is low levels of thyroid hormones after radiation therapy to the neck. Likewise, your dentist will help to prevent cavities, jaw decay, and infections.

Follow-up care may involve working with specialists. You may need to work with a speech-language pathologist to improve speech or swallowing. A dietician can help you get good nutrition. Mental health providers can help you quit smoking and limit alcohol.

## Recurrence

Doctors call the return of cancer a recurrence. Treatment is partly based on where the cancer returns. Your prior treatment is important, too.

Some recurrences can be treated with surgery. Radiation therapy with or without systemic therapy may follow. When surgery is not an option, radiation therapy, systemic therapy, or both may be given. Also, ask your doctor if there is a clinical trial that is right for you.

## Review

- Treatment for advanced oral cancers is based on whether you can have surgery. Other options include radiation therapy with or without systemic therapy and clinical trials.
- Visit your cancer doctor for follow-up care. He or she will assess for any new signs of cancer. Also, tell your doctor about any new or worse symptoms. Health problems from cancer treatments may start during follow-up.
- After cancer treatment, you may need help to improve your talking and eating.
- Oral cancer may return after a cancer-free period. Tests of the cancer will be used to tailor treatment to you.



Take control, or be controlled.

– Hank

14-year cancer survivor

Stage IV tongue cancer

# 5

## Treatment guide: Stages IVB (T4b) and IVC

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This chapter presents the treatment options for very advanced oral cancers. Discuss the pros and cons of treatment with your doctor. He or she can help you decide what is right for you.

## Performance status

For very advanced cancers, treatment options are partly based on performance status. See [Guide 5](#). Performance status is your ability to do daily activities. The ECOG (Eastern Cooperative Oncology Group) Performance Scale 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.

## Treatment

Treatment options for very advanced cancers are listed in [Guide 5](#). Options are grouped by cancer stage. A clinical trial may be an option, too. Ask your doctor if there is a clinical trial that is right for you.

### Systemic therapy with radiation therapy

If you are healthy enough, you may get systemic therapy and radiation therapy during the same time frame. This treatment is called concurrent chemoradiation. It has better outcomes than radiation therapy alone but can cause severe side effects. Options for systemic therapy are listed in [Guide 6](#).

Another approach is to receive only chemotherapy as the first treatment. This is called induction chemotherapy. It may be followed by radiation therapy with or without systemic therapy. More research is needed to learn if induction chemotherapy improves outcomes. To date, research has not shown that it extends life.

### Radiation therapy

Radiation therapy for very advanced cancers is used for multiple purposes. As noted above, it may be used with systemic therapy for cancer control. It may also be used alone to control the growth of metastases. As noted below, it may be used for supportive care.

For some very advanced cancers, radiation therapy may be used as the main treatment. When used for this purpose, it is called definitive radiation therapy. Stronger doses of radiation therapy will be given.

Imaging will be used to check radiation results. It is often done 10 to 12 weeks after the last radiation session. Your doctor will use the results to plan the next steps of treatment.

## Guide 5. Treatment for very advanced cancers

Cancer stage	What are the options?
Stage IVB (T4b)	<b>Performance score 0 or 1</b> <ul style="list-style-type: none"> <li>• Concurrent chemoradiation</li> <li>• Radiation therapy ± systemic therapy</li> </ul>
	<b>Performance score 2</b> <ul style="list-style-type: none"> <li>• Radiation therapy ± concurrent systemic therapy</li> </ul>
	<b>Performance score 3 or 4</b> <ul style="list-style-type: none"> <li>• Radiation therapy for supportive care</li> <li>• Single-agent systemic therapy</li> <li>• Best supportive care</li> </ul>
Stage IVC	<b>Performance score 0 or 1</b> <ul style="list-style-type: none"> <li>• Systemic therapy (single or multiple agents)</li> <li>• Surgery, radiation therapy, or systemic therapy with radiation therapy if metastases are limited</li> <li>• Best supportive care</li> </ul>
	<b>Performance score 2</b> <ul style="list-style-type: none"> <li>• Single-agent systemic therapy</li> <li>• Best supportive care</li> </ul>
	<b>Performance score 3 or 4</b> <ul style="list-style-type: none"> <li>• Best supportive care</li> </ul>

## Guide 6. Systemic therapy with concurrent radiation therapy

What regimens are used?
• High-dose cisplatin
• Cetuximab
• Carboplatin + infusional 5-FU
• 5-FU + hydroxyurea
• Cisplatin + paclitaxel
• Cisplatin + infusional 5-FU
• Carboplatin + paclitaxel
• Weekly cisplatin



My cancer journey is not a sad story. I still struggle some days, and the months after my diagnosis were the most trying, difficult, and painful of my life. But my medical team, my community, my family and friends were amazing.

– Ryan

5-year cancer survivor  
Stage IV tongue cancer

## Systemic therapy

Systemic therapy without other treatments is used to treat some oral cancers. 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.

The first cancer drugs given are called first-line therapy. Options for first-line therapy are listed in [Guide 7](#). If first-line therapy stops working, you may be given other cancer drugs. This is called

## Guide 7. First-line systemic therapy

### What combination regimens are used?

- Cisplatin + 5-FU + cetuximab or
- Carboplatin + 5-FU + cetuximab
- Cisplatin + docetaxel or paclitaxel or
- Carboplatin + docetaxel or paclitaxel
- Cisplatin + cetuximab
- Cisplatin + 5-FU
- Cisplatin + docetaxel + cetuximab or
- Carboplatin + docetaxel + cetuximab
- Cisplatin + paclitaxel + cetuximab or
- Carboplatin + paclitaxel + cetuximab

### What single-agent regimens are used?

- Cisplatin
- Carboplatin
- Paclitaxel
- 5-FU
- Methotrexate
- Cetuximab
- Gemcitabine
- Capecitabine

second-line therapy. Options for second- and next-in-line therapy include first-line options not given. Nivolumab, pembrolizumab, and afatinib are also options.

## Surgery for metastases

Surgery may be an option for some metastatic cancers. 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 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.

## Review

- Your doctor will plan treatment based on your performance status.
- If you are healthy enough, systemic therapy, radiation therapy, or both may be given to control cancer growth.
- If you are too frail, treatment to improve your quality of life may be given.

# 6

## Making treatment decisions

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WHAT  
SHOULD  
I DO



Having cancer is very stressful. While absorbing the fact that you have cancer, you have to learn about tests and treatments. In addition, the time you have to accept a treatment plan feels short. Parts 1 through 5 described oral cancers and treatment options. This chapter aims to help you make decisions that are in line with your beliefs, wishes, and values.

## It's your choice

The role patients want in choosing their treatment differs. You may feel uneasy about making treatment decisions. This may be due to a high level of stress. It may be hard to hear or know what others are saying. Stress, pain, and drugs can limit your ability to make good decisions. You may feel uneasy because you don't know much about cancer. You've never heard the words used to describe cancer, tests, or treatments. Likewise, you may think that your judgment isn't any better than your doctors'.

Letting others decide which option is best may make you feel more at ease. But, whom do you want to make the decisions? You may rely on your doctors alone to make the right decisions. However, your doctors may not tell you which to choose if you have multiple good options. You can also have loved ones help. They can gather information, speak on your behalf, and share in decision-making with your doctors. Even if others decide which treatment you will receive, you still have to agree by signing a consent form.

On the other hand, you may want to take the lead or share in decision-making. Most patients do. In shared decision-making, you and your doctors share information, weigh the options, and agree on a treatment plan. Your doctors know the science

behind your plan but you know your concerns and goals. By working together, you are likely to get a higher quality of care and be more satisfied. You'll likely get the treatment you want, at the place you want, and by the doctors you want.

## Questions to ask

You may meet with experts from different fields of medicine. Prepare questions before your visit and ask questions if the person isn't clear. You can take notes and get copies of your medical records.

It may be helpful to have your spouse, partner, or a friend with you at these visits. A patient advocate or navigator might also be able to come. They can help to ask questions and take notes. Suggested questions to ask are listed on the following pages.



I want to know what the choices are and what the known risks and benefits are. I question a lot.

– Michael

Cancer survivor

Head and neck cancer

## What's my diagnosis and prognosis?

It's important to know that there are different types of cancer. Cancer can greatly differ even when people have a tumor in the same organ. Based on your test results, your doctor can tell which type of cancer you have. He or she can also give a prognosis. A prognosis is a prediction of the pattern and outcome of a disease. Knowing the prognosis may affect what you decide about treatment.

1. Where did the cancer start? In what type of cell? Is this cancer common?
2. Is this a fast- or slow-growing cancer?
3. What tests do you recommend for me?
4. Where will the tests take place? How long will the tests take and will any test hurt?
5. What if I am pregnant?
6. How do I prepare for testing?
7. Should I bring a list of my medications?
8. Should I bring someone with me?
9. How often are these tests wrong?
10. Would you give me a copy of the pathology report and other test results?
11. Who will talk with me about the next steps? When?

## What are my options?

There is no single treatment practice that is best for all patients. There is often more than one treatment option along with clinical trial options. Your doctor will review your test results and recommend treatment options.

1. What will happen if I do nothing?
2. Can I just carefully monitor the cancer?
3. Do you consult NCCN recommendations when considering options?
4. Are you suggesting options other than what NCCN recommends? If yes, why?
5. Do your suggested options include clinical trials? Please explain why.
6. How do my age, health, and other factors affect my options? What if I am pregnant?
7. How will treatment affect my looks, speech, chewing, and swallowing? Will my sense of smell or taste change?
8. Which option is proven to work best?
9. Which options lack scientific proof?
10. What are the benefits of each option? 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?
11. What are the risks of each option? What are possible complications? What are the rare and common side effects? Short-lived and long-lasting side effects? Serious or mild side effects? Other risks?
12. How do you know if treatment is working?
13. What are my options if my treatment stops working?
14. What can be done to prevent or relieve the side effects of treatment?

## What does each option require of me?

Many patients consider how each option will practically affect their lives. This information may be important because you have family, jobs, and other duties to take care of. You also may be concerned about getting the help you need. If you have more than one option, choosing the option that is the least taxing may be important to you.

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?



## Deciding between options

Deciding which option is best can be hard. Doctors from different fields of medicine may have different opinions on which option is best for you. This can be very confusing. Your spouse or partner may disagree with which option you want. This can be stressful. In some cases, one option hasn't been shown to work better than another. Some ways to decide on treatment are discussed next.

### 2<sup>nd</sup> opinion

The time around a cancer diagnosis is very stressful. People with cancer often want to get treated as soon as possible. They want to make their cancer go away before it spreads farther. While cancer can't be ignored, there is time to think about and choose which option is best for you.

You may wish to have another doctor review your test results and suggest a treatment plan. This is called getting a 2<sup>nd</sup> opinion. You may completely trust your doctor, but a 2<sup>nd</sup> opinion on which option is best can help.

Copies of the pathology report, imaging tests, and other test results need to be sent to the doctor giving the 2<sup>nd</sup> opinion. Some people feel uneasy asking for copies from their doctors. However, a 2<sup>nd</sup> opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What's more, some health plans require a 2<sup>nd</sup> opinion. If your health plan doesn't cover the cost of a 2<sup>nd</sup> opinion, you have the choice of paying for it yourself.

If the two opinions are the same, you may feel more at peace about the treatment you accept to have. If the two opinions differ, think about getting a 3<sup>rd</sup> opinion. A 3<sup>rd</sup> opinion may help you decide between your options. Choosing your cancer treatment is a

very important decision. It can affect your length and quality of life.

### Support groups

Besides talking to health experts, it may help to talk to patients who have walked in your shoes. Support groups often consist of people at different stages of treatment. Some may be in the process of deciding while others may be finished with treatment. At support groups, you can ask questions and hear about the experiences of other people with oral cancer.

### Compare benefits and downsides

Every option has benefits and downsides. Consider these when deciding which option is best for you. Talking to others can help identify benefits and downsides you haven't thought of. Scoring each factor from 0 to 10 can also help since some factors may be more important to you than others.

## Websites

### American Cancer Society

[cancer.org/cancer/oral-cavity-and-oropharyngeal-cancer.html](https://cancer.org/cancer/oral-cavity-and-oropharyngeal-cancer.html)

### Head and Neck Cancer Alliance (HNCA)

[headandneck.org](https://headandneck.org)

### National Cancer Institute (NCI)

[cancer.gov/types/head-and-neck](https://cancer.gov/types/head-and-neck)

### NCCN for Patients®

[nccn.org/patients](https://nccn.org/patients)

### Oral Cancer Foundation

[oralcancerfoundation.org](https://oralcancerfoundation.org)

### smokefree.gov

[smokefree.gov](https://smokefree.gov)

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

[spohnc.org](https://spohnc.org)

## Review

- Shared decision-making is a process in which you and your doctors plan treatment together.
- Asking your doctors questions is vital to getting the information you need to make informed decisions.
- Getting a 2<sup>nd</sup> opinion, attending support groups, and comparing benefits and downsides may help you decide which treatment is best for you.

## Help services

- ✓ HNCA Helpline  
866-916-5107  
Monday–Friday  
9 AM to 9 PM ET
- ✓ HNCA Online Support Community  
[inspire.com/groups/head-and-neck-cancer-alliance](https://inspire.com/groups/head-and-neck-cancer-alliance)
- ✓ OCF Head and Neck Cancer screening  
[oralcancerfoundation.org/screening](https://oralcancerfoundation.org/screening)
- ✓ SPOHNC local support groups  
800-377-0928  
[info@spohnc.org](mailto:info@spohnc.org)
- ✓ SPOHNC National Survivor Volunteer Network (NSVN)  
This unique matching service pairs volunteers who have gone through diagnosis, treatment, and recovery with patients or caregivers who are just beginning their journey, or now recovering from side effects of cancer or its treatment.  
800-377-0928  
[info@spohnc.org](mailto:info@spohnc.org)

# Glossary

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# Dictionary

## **adjuvant therapy**

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

## **alveolar ridge**

The gums around the base of your teeth.

## **anesthesia**

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

## **anterior tongue**

The first two-thirds of your tongue.

## **biopsy**

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

## **boost**

An extra dose of radiation to a specific area of the body.

## **brachytherapy**

A treatment with radiation from an object placed near or in the tumor. Also called internal radiation.

## **buccal mucosa**

The insides of the cheeks.

## **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.

## **concurrent chemoradiation**

A treatment of cell-killing drugs and high-energy rays that are given during the same time period.

## **definitive radiation therapy**

Treatment with radiation used to try to cure the cancer.

## **dental exam**

A study of your teeth and gums.

## **deoxyribonucleic acid (DNA)**

A chain of chemicals in cells that contains coded instructions for making and controlling cells. Also called the "blueprint of life."

## **distress**

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

## **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.

## **fine-needle aspiration (FNA)**

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

## **gene**

Coded instructions in cells for making new cells and controlling how cells behave.

## **hard palate**

The bony roof of your mouth.

## **imaging**

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

## **immune system**

The body's natural defense against infection and disease.

## **immunotherapy**

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

## **induction chemotherapy**

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

## **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.

**mutation**

An abnormal change.

**neck dissection**

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

**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.

**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.

**prosthodontic exam**

A study of your mouth to prepare for restoring its look and function.

**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.

**retromolar trigone**

The gums behind your wisdom teeth.

**sentinel lymph node**

The first lymph node to which cancer cells spread after leaving a tumor.

**sentinel lymph node biopsy**

An operation to remove the disease-fighting structures (lymph nodes) to which cancer first spreads. Also called sentinel lymph node dissection.

**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.

# Acronyms

**3-D**

three-dimensional

**3D-CRT**

three-dimensional conformal radiation therapy

**AJCC**

American Joint Committee on Cancer

**CT**

computed tomography

**DNA**

deoxyribonucleic acid

**EBRT**

external beam radiation therapy

**ECOG**

Eastern Cooperative Oncology Group

**EGFR**

epidermal growth factor receptor

**FDG**

fluorodeoxyglucose

**FNA**

fine-needle aspiration

**IMRT**

intensity-modulated radiation therapy

**MRI**

magnetic resonance imaging

**PEG**

percutaneous endoscopic gastrostomy

**PET**

positron emission tomography

# NCCN Panel Members for Head and Neck Cancers

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For disclosures, visit [www.nccn.org/about/disclosure.aspx](http://www.nccn.org/about/disclosure.aspx).

# NCCN Member Institutions

Abramson Cancer Center  
at the University of Pennsylvania  
Philadelphia, Pennsylvania  
800.789.7366  
[pennmedicine.org/cancer](http://pennmedicine.org/cancer)

Fred & Pamela Buffett Cancer Center  
Omaha, Nebraska  
800.999.5465  
[nebraskamed.com/cancer](http://nebraskamed.com/cancer)

Case Comprehensive Cancer Center/  
University Hospitals Seidman Cancer  
Center and Cleveland Clinic Taussig  
Cancer Institute  
Cleveland, Ohio  
800.641.2422 • UH Seidman Cancer Center  
[uhhospitals.org/seidman](http://uhhospitals.org/seidman)  
866.223.8100 • CC Taussig Cancer Institute  
[my.clevelandclinic.org/services/cancer](http://my.clevelandclinic.org/services/cancer)  
216.844.8797 • Case CCC  
[case.edu/cancer](http://case.edu/cancer)

City of Hope National Medical Center  
Los Angeles, California  
800.826.4673  
[cityofhope.org](http://cityofhope.org)

Dana-Farber/Brigham and  
Women's Cancer Center  
Massachusetts General Hospital  
Cancer Center  
Boston, Massachusetts  
877.332.4294  
[dfbwcc.org](http://dfbwcc.org)  
[massgeneral.org/cancer](http://massgeneral.org/cancer)

Duke Cancer Institute  
Durham, North Carolina  
888.275.3853  
[dukecancerinstitute.org](http://dukecancerinstitute.org)

Fox Chase Cancer Center  
Philadelphia, Pennsylvania  
888.369.2427  
[foxchase.org](http://foxchase.org)

Huntsman Cancer Institute  
at the University of Utah  
Salt Lake City, Utah  
877.585.0303  
[huntsmancancer.org](http://huntsmancancer.org)

Fred Hutchinson Cancer  
Research Center/Seattle  
Cancer Care Alliance  
Seattle, Washington  
206.288.7222 • [seattlecca.org](http://seattlecca.org)  
206.667.5000 • [fredhutch.org](http://fredhutch.org)

The Sidney Kimmel Comprehensive  
Cancer Center at Johns Hopkins  
Baltimore, Maryland  
410.955.8964  
[hopkinskimmelcancercenter.org](http://hopkinskimmelcancercenter.org)

Robert H. Lurie Comprehensive Cancer  
Center of Northwestern University  
Chicago, Illinois  
866.587.4322  
[cancer.northwestern.edu](http://cancer.northwestern.edu)

Mayo Clinic Cancer Center  
Phoenix/Scottsdale, Arizona  
Jacksonville, Florida  
Rochester, Minnesota  
800.446.2279 • Arizona  
904.953.0853 • Florida  
507.538.3270 • Minnesota  
[www.mayoclinic.org/cancercenter](http://www.mayoclinic.org/cancercenter)

Memorial Sloan Kettering  
Cancer Center  
New York, New York  
800.525.2225  
[mskcc.org](http://mskcc.org)

Moffitt Cancer Center  
Tampa, Florida  
800.456.3434  
[moffitt.org](http://moffitt.org)

The Ohio State University  
Comprehensive Cancer Center -  
James Cancer Hospital and  
Solove Research Institute  
Columbus, Ohio  
800.293.5066  
[cancer.osu.edu](http://cancer.osu.edu)

O'Neal Comprehensive  
Cancer Center at UAB  
Birmingham, Alabama  
800.822.0933  
[uab.edu/onealcancercenter/](http://uab.edu/onealcancercenter/)

Roswell Park Comprehensive  
Cancer Center  
Buffalo, New York  
877.275.7724  
[roswellpark.org](http://roswellpark.org)

Siteman Cancer Center at Barnes-  
Jewish Hospital and Washington  
University School of Medicine  
St. Louis, Missouri  
800.600.3606  
[siteman.wustl.edu](http://siteman.wustl.edu)

St. Jude Children's  
Research Hospital  
The University of Tennessee  
Health Science Center  
Memphis, Tennessee  
888.226.4343 • [stjude.org](http://stjude.org)  
901.683.0055 • [westclinic.com](http://westclinic.com)

Stanford Cancer Institute  
Stanford, California  
877.668.7535  
[cancer.stanford.edu](http://cancer.stanford.edu)

UC San Diego Moores Cancer Center  
La Jolla, California  
858.657.7000  
[cancer.ucsd.edu](http://cancer.ucsd.edu)

UCSF Helen Diller Family  
Comprehensive Cancer Center  
San Francisco, California  
800.689.8273  
[cancer.ucsf.edu](http://cancer.ucsf.edu)

University of Colorado Cancer Center  
Aurora, Colorado  
720.848.0300  
[coloradocancercenter.org](http://coloradocancercenter.org)

University of Michigan  
Rogel Cancer Center  
Ann Arbor, Michigan  
800.865.1125  
[mcancer.org](http://mcancer.org)

The University of Texas  
MD Anderson Cancer Center  
Houston, Texas  
800.392.1611  
[mdanderson.org](http://mdanderson.org)

University of Wisconsin  
Carbone Cancer Center  
Madison, Wisconsin  
608.265.1700  
[uwhealth.org/cancer](http://uwhealth.org/cancer)

Vanderbilt-Ingram Cancer Center  
Nashville, Tennessee  
800.811.8480  
[vicc.org](http://vicc.org)

Yale Cancer Center/  
Smilow Cancer Hospital  
New Haven, Connecticut  
855.4.SMILOW  
[yalecancercenter.org](http://yalecancercenter.org)



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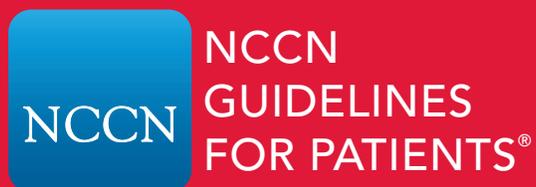
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# Oral Cancers

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[NCCN.org/patients](http://NCCN.org/patients) – For Patients | [NCCN.org](http://NCCN.org) – For Clinicians