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FOR PATIENTS®

2024

Mouth Cancer



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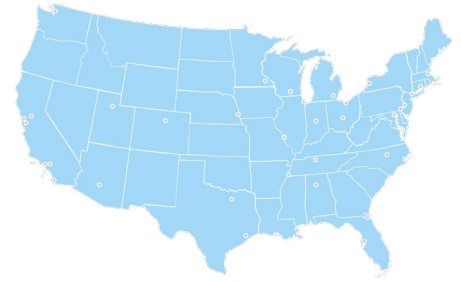
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About the NCCN Guidelines for Patients®



Did you know that top cancer centers across the United States work together to improve cancer care? This alliance of leading cancer centers is called the National Comprehensive Cancer Network® (NCCN®).



Cancer care is always changing. NCCN develops evidence-based cancer care recommendations used by health care providers worldwide. These frequently updated recommendations are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). The NCCN Guidelines for Patients plainly explain these expert recommendations for people with cancer and caregivers.

These NCCN Guidelines for Patients are based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Head and Neck Cancers Version 1.2024 – October 9, 2023.

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Mouth cancer basics

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Mouth or oral cavity cancer is a type of cancer that affects the lips, the front two-thirds of the tongue, the gums, the lining inside the cheeks and lips, the floor (bottom) of the mouth under the tongue, the hard palate (bony top of the mouth), the bony ridges that hold the sockets of the teeth, and the small area of the gum behind the wisdom teeth.

- **Tongue** is a muscular organ in your mouth that aids in chewing, speaking, and breathing.
- **Lips** surround the opening of the mouth.
- **Buccal (oral) mucosa** is the lining inside the cheeks and inside where the lips touch the teeth.
- **Alveolar ridge** is the bony, raised area of the upper (maxilla) and lower (mandible) jaw that holds the sockets of the teeth.
- **Gums (gingiva)** surround the base of the teeth and help keep them in place.
- **Retromolar trigone** is the small area behind the wisdom teeth.

The mouth

The mouth, or oral cavity, is the first part of the digestive and respiratory (breathing) systems. The lips, cheeks, palate, teeth, and tongue make up the mouth. The mouth helps us breathe, talk, chew, taste, swallow, eat, and drink. The cheeks and lips hold food in the mouth and help to form and sound words.

Parts of the mouth

The 2 main functions of the mouth are eating and speaking. The mouth is also known as the oral cavity or the buccal cavity.

Some important structures of the mouth:

- **Hard palate** is the hard, bony part of the roof of the mouth.

Oral mucosa

The oral mucosa is the mucous membrane lining the inside of the mouth and lips.

It is made up of 2 layers.

1. **Epithelium** – The surface layer containing stratified squamous cells, which are thin, flat cells.
2. **Lamina propria** – The bottom layer of connective tissue.

A tumor can grow through the layers of the oral mucosa. A measure of how deep the tumor has grown is called depth of invasion (DOI).

Depending on the region of the mouth, the epithelium may be nonkeratinized or keratinized. Nonkeratinized squamous epithelium covers the soft palate, inner lips, inner cheeks, the floor of the mouth, and area underneath the tongue. Keratinized squamous

epithelium is present on rough surfaces caused by chewing such as the gums (gingiva) and hard palate as well as the top of the tongue.

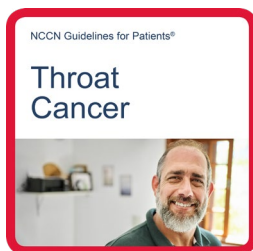
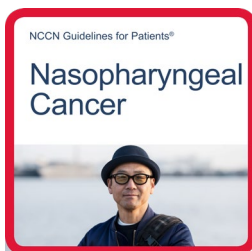
Head and neck cancer

Head and neck cancer is a group of cancers that arise in the head or neck area of the body. Cancer is named and treated based on the tumor location or where the cancer started.

Cancer can occur in the

- Mouth (oral cavity),
- Middle part of the throat near the mouth (oropharynx),
- Space behind the nose (nasal cavity and paranasal sinuses),
- Upper part of the throat near the nasal cavity (nasopharynx),
- Voice box (larynx), or
- Lower part of the throat near the voice box (hypopharynx).

More information on nasopharyngeal cancer (NPC) and throat (oropharyngeal) cancer can be found at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.



It is strongly recommended, when possible, for those with head and neck cancers to be treated at a high-volume center or hospital that has experience in their type of cancer.

Mouth cancer

Cancer that occurs on the inside of the mouth is also called oral cancer or oral cavity cancer. Mouth cancer is one of several types of cancers grouped into a category called head and neck cancers. Mouth cancer and other head and neck cancers are often treated similarly.

Mouth cancer starts in the squamous cells that form the surface lining of the mouth. Normally, these are thin, flat cells and are similar to the top layer of skin and surface lining some other parts of the body such as the lungs and esophagus. Squamous cell carcinoma (SCC) is the most common type of mouth cancer and is the focus of this book.

Mouth cancer can develop in the parts that make up the mouth such as:

- Lips (mucosal lip)
- Gums (gingiva)
- Lining inside the cheeks and lips (buccal mucosa)
- Front two-thirds of the tongue
- Roof of the mouth (hard palate)

- Bony, raised areas that hold the teeth sockets (alveolar ridge)
- Floor of the mouth (under the tongue)
- Small area of the gum behind the wisdom teeth (retromolar trigone)

Cutaneous squamous cell carcinoma of the vermilion lip is not included in this book. The vermilion lip is the area where the skin and the lip meet on the outside of the mouth. Information for treatment of cutaneous squamous cell carcinoma of the vermilion lip can be found in NCCN Guidelines for Patients: Squamous Cell Skin Cancer at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](https://www.nccn.org/patientguidelines) app.

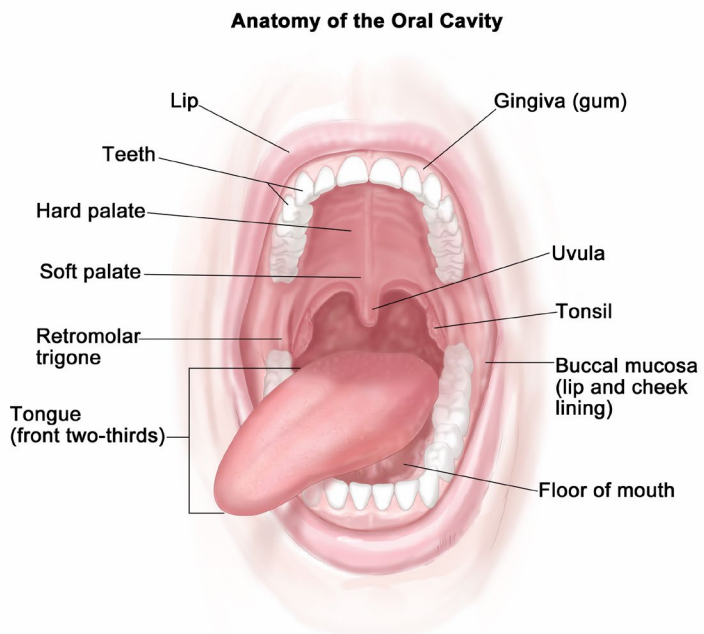


Key points

- Mouth cancer refers to cancer that develops in any of the parts that make up the mouth (oral cavity). Mouth cancer is a type of head and neck cancer.
- Head and neck cancers are a group of cancers that arise in the head or neck area of the body.
- Cancer treatment is based on the tumor location and cancer stage.
- Squamous cell carcinoma (SCC) is the most common type of mouth cancer. It forms in the thin, flat cells of the mucous membranes of the mouth. SCC is the focus of this book.

Mouth cancer

Mouth or oral cancer can develop in the lips (mucosal lip), the lining inside the cheeks and lips (buccal mucosa), the front two-thirds of the tongue, the upper and lower gums (gingiva), the floor of the mouth under the tongue, the bony roof of the mouth (hard palate), and the small area behind the wisdom teeth (retromolar trigone).



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Testing for mouth cancer

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Treatment planning starts with testing. This chapter presents an overview of the tests you might receive and what to expect.

Test results

Results from imaging studies and biopsy will be used to determine your cancer stage treatment plan. Treatment will be based on these findings. It is important you understand what these tests mean. Ask questions and keep copies of your test results. Online patient portals are a great way to access your test results. Please discuss your results with your health care provider.

Keep these things in mind:

- Choose a friend, family member, or peer who can drive you to appointments,

provide meals, or offer emotional support during diagnosis and treatment.

- Bring someone with you to doctor visits, if possible.
- Write down questions and take notes during appointments. Don't be afraid to ask your care team questions. Get to know your care team and help them get to know you.
- Get copies of blood tests, imaging results, and reports about the specific type of cancer you have.
- Organize your papers. Create files for insurance forms, medical records, and test results. You can do the same on your computer.
- Keep a list of contact information for everyone on your care team. Add it to your phone. Hang the list on your refrigerator or keep it in a place where someone can access it in an emergency. Keep your primary care physician (PCP) informed of changes to this list. You are

Take care of yourself. This is a stressful time. Seek out support groups at your local hospital, through social media, or from those listed in the back of this book. Look to friends, relatives, neighbors, and coworkers for social support.



encouraged to keep your PCP in the loop. They are great partners in your care.

- In your contact list, include information on the exact type of cancer you have, as well as any treatments you've received and the date each treatment started.
- Set up a “MyChart” or health record account if it’s available, which will help you track your appointments and communicate with your care team.

General health tests

Some general health tests are described next.

Medical history

A medical history is a record of all health issues and treatments you have had in your life. Be prepared to list any illness or injury

and when it happened. Bring a list of old and new medicines and any over-the-counter (OTC) medicines, herbals, or supplements you take. Some supplements interact and affect medicines that your care team may prescribe. Tell your care team about any symptoms you have. A medical history, sometimes called a health history, will help determine which treatment is best for you.

Family history

In general, head and neck cancers are not inherited from your biological parents. However, some cancers and other diseases can run in families. Your care team will ask about the health history of family members who are blood relatives. This information is called a family history. Ask family members on both sides of your family about their health issues like heart disease, cancer, and diabetes, and at what age they were

Guide 1

Tests for treatment planning

Medical history, tobacco and alcohol use history, and physical exam, including complete head and neck exam. Mirror and fiberoptic exam if needed. Screen for depression.

Biopsy

As needed:

- Chest CT (with or without contrast)
- CT with contrast and/or MRI with and without contrast of primary tumor and neck
- FDG-PET/CT
- Endoscopy with examination under anesthesia (EUA)
- Dental exam with x-ray (Panorex) or CT without contrast
- Nutrition, speech, and swallowing evaluation, and hearing test (audiogram)
- Help to quit smoking
- Fertility counseling
- Screening for hepatitis B

diagnosed. It's important to know the specific type of cancer or where the cancer started, if it is in multiple locations, and if they had genetic testing.

Tobacco and alcohol use history

Tobacco and alcohol use are known risk factors for developing head and neck cancer and can limit how well treatment works. It can affect survival. You will be asked about your tobacco and alcohol use history and asked to avoid tobacco and limit alcohol use during treatment. Speak to your care team if you have any questions or concerns.

Physical exam

During a physical exam, your health care provider may:

- Check your temperature, blood pressure, pulse, and breathing rate
- Check your height and weight
- Listen to your lungs and heart
- Look in your eyes, ears, nose, and throat
- Feel and apply pressure to parts of your body to see if organs are of normal size, are soft or hard, or cause pain when touched.
- Feel for enlarged lymph nodes in your neck, underarm, and groin.

Complete head and neck exam

A physical exam will include the head and neck. Since some parts of the mouth and throat are not easy to see when you open your mouth, a health care provider might feel (palpate) your oral cavity and use a special

mirror or fiberoptic scope to look at these areas.

Dental exam

It is important to tell your dentist about your head and neck cancer and to have regular dental cleanings and checkups. Head and neck cancer and its treatment can affect the health of your jaw, teeth, and gums. If you need any dental work or procedures, it might be recommended before starting certain treatments.

Distress screening

It is normal to have strong feelings about being diagnosed with cancer and your feelings can also change from day to day and week to week. Talk to your care team and those whom you feel most comfortable about how you are feeling. There are services and people who can help you. Support and counseling are available. Many treatment teams include mind and body therapists who can help.

Dealing with a cancer diagnosis can be stressful and may cause further distress. Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect how you feel, think, and act. Distress might include feelings of sadness, fear, helplessness, worry, anger, and guilt. You may also experience depression, anxiety, and sleep issues. Your treatment team will screen your level of distress. This is part of your cancer care.

Your diagnosis of cancer may affect your family or loved ones. They may feel some degree of anxiety or depression. They can talk to the social worker and seek help, too.

Endocrine tests

Radiation therapy to the head and neck can affect endocrine (hormone) glands found in the head and neck, such as thyroid and pituitary glands. Therefore, blood tests to look at thyroid endocrine levels might be done before and/or after treatment.

Hearing test

A hearing test shows if there is any hearing loss, and if so, the type of hearing loss, how severe it is, and what might have caused it. An audiogram is a graph showing the results of a pure-tone hearing test. Tumors in the head and neck can affect hearing. Treatment of head and neck tumors can also affect hearing.

Nutrition assessment

You might meet with a nutrition expert before starting treatment. A nutritionist or dietitian can suggest the best foods and fluids for you. It is important that you receive adequate and sustained nutrition before you start treatment.

Speech and swallowing assessment

You might visit with a speech or swallowing therapist who will test your ability to swallow and speak before and after treatment.

Performance status

Performance status (PS) is a person's general level of fitness and ability to perform daily self-care tasks. Your state of general health will be rated using a PS scale called Eastern Cooperative Oncology Group (ECOG). PS is one factor taken into consideration when

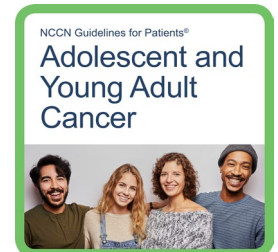
choosing a treatment plan. Your preferences about treatment are always important.

Fertility (all genders)

Treatment such as chemotherapy can affect your fertility, the ability to have children. If you think you want children in the future, ask your care team how cancer and cancer treatment might change your fertility. To preserve your fertility, you may need to take action before starting cancer treatment. Those who want to have children in the future should be referred to a fertility specialist to discuss the options before starting treatment.

Fertility preservation is all about keeping your options open, whether you know you want to have children later in life or aren't really sure at the moment. Fertility and reproductive specialists can help you sort through what may be best for your situation.

More information on fertility preservation in adolescents and young adults is available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.



Changes in fertility

Treatment might cause your fertility to be temporarily or permanently impaired or interrupted. This loss of fertility is related to your age at time of diagnosis, treatment type(s), treatment dose, and treatment length. Talk to your care team about your concerns and if you are planning a pregnancy.

Preventing pregnancy during treatment

Preventing pregnancy during treatment is important. Cancer and cancer treatment can affect the ovaries and damage sperm. Hormonal birth control may or may not be recommended, so ask your doctor about options such as intrauterine devices (IUDs) and barrier methods. Types of barrier methods include condoms, diaphragms, cervical caps, and the contraceptive sponge.

Those with ovaries

Those who can become pregnant will have a pregnancy test before starting treatment. Cancer treatment can hurt the developing baby if you are or become pregnant during treatment. Therefore, birth control to prevent pregnancy during and after treatment is recommended. If you are pregnant or breastfeeding at the time of your cancer diagnosis, certain treatments will need to be avoided.

Menstruation, menses, menstrual flow, or your “period” may stop during treatment, but often returns within 2 years after treatment in those 35 years of age and under. It is still possible to become pregnant even though you might not have a period. Therefore, birth control is recommended during and after treatment. Consult your doctor for the best time to plan a pregnancy.

Those with testicles

Cancer and cancer treatment can damage sperm. Therefore, use contraception (birth control) such as condoms to prevent pregnancy during and immediately after cancer treatment.



Create a medical binder

A medical binder or notebook is a great way to organize all of your records in one place.

- ✓ Make copies of blood tests, imaging results, and reports about your specific type of cancer. It will be helpful when getting a second opinion.
- ✓ Choose a binder that meets your needs. Consider a zipper pocket to include a pen, small calendar, and insurance cards.
- ✓ Create folders for insurance forms, test types (ie, blood, imaging, pathology, radiology, genetics), treatments, and procedures. Organize items in the folder by date.
- ✓ Use online patient portals to view your test results and other records. Download or print the records to add to your binder.
- ✓ Add a section for questions and to take notes.

Bring your medical binder to appointments. You never know when you might need it!

Imaging tests

Imaging tests take pictures of the inside of your body. Imaging tests show the primary tumor, or where the cancer started, and look for cancer in other parts of the body. A radiologist, an expert in interpreting imaging tests, will write a report and send this report to your health care provider (HCP). It is likely that the report will be sent directly to you through your patient portal or patient access system. You should discuss these results with your HCP. You will not have all of the following tests.

Contrast material

Contrast material is used to improve the pictures of the inside of the body. Contrast materials are not dyes, but substances that help enhance and improve the images of several organs and structures in the body. It is used to make the pictures clearer. The contrast is not permanent and will leave your body in your urine immediately after the test. The types of contrast vary and are different for CT and MRI.

Tell your care team if you have had allergic reactions to contrast in the past. This is important. You might be given medicines to avoid the effects of those allergies. Contrast might not be used if you have a serious allergy or if your kidneys aren't working well.

CT scan

A computed tomography (CT or CAT) scan uses x-rays and computer technology to take pictures of the inside of the body. It takes many x-rays of the same body part from different angles. All the images are combined to make one detailed picture. A CT scan of your head, neck, and chest, may be one of the tests to

look for cancer. In most cases, contrast will be used.

MRI scan

A magnetic resonance imaging (MRI) scan uses radio waves and powerful magnets to take pictures of the inside of the body. It does not use x-rays. Because of the very strong magnets used in the MRI machine, tell the technologist if you have any metal in your body. During the test, you will likely be asked to hold your breath for 10 to 20 seconds as the technician collects the images. Contrast is often used.

A closed MRI has a capsule-like design where the magnet surrounds you. An open MRI has a magnetic top and bottom, which allows for an opening on each end. Closed MRIs are more common than open MRIs, so if you have claustrophobia (a dread or fear of enclosed spaces), be sure to talk to your care team about it.

PET scan

A positron emission tomography (PET) scan uses a radioactive drug called a tracer. A tracer is a substance injected into a vein to see where cancer cells are in the body and if they are using sugar produced by your body to grow. Cancer cells show up as bright spots on PET scans. However, not all tumors will appear on a PET scan. Also, not all bright spots are cancer. **It is normal for the brain, base of the tongue or tonsil lymphoid tissue, heart, kidneys, and bladder to be bright on PET.** Inflammation or infection can also show up as a bright spot. When a PET scan is combined with CT, it is called a PET/CT scan.

FDG-PET/CT

An FDG-PET/CT uses a radiotracer called fluorodeoxyglucose (FDG). It is made of fluoride and a simple form of sugar called glucose. You cannot eat or drink for at least 4 hours before the scan. This scan is most helpful when other imaging results are unclear. It may help find cancer in lymph nodes and distant sites. If it clearly shows cancer in the bone, a bone scan and sodium fluoride PET/CT may not be needed. FDG-PET/CT can be done at the same time as a CT used for diagnosis.

Ultrasound

Ultrasound (US) uses high-energy sound waves to form pictures of the inside of the body. This is similar to the sonogram used for pregnancy. A wand-like probe (transducer) will be held and moved on your neck using gel. Ultrasound is painless and does not use x-rays, so it can be repeated as needed. Ultrasound is good at showing small areas of cancer that are near the skin. Sometimes, an ultrasound or CT is used to guide a biopsy.

Panoramic dental x-ray

A panoramic dental x-ray or panoramic x-ray (Panorex) uses a very small dose of radiation to capture the entire mouth in one image, including the teeth, upper and lower jaws, and surrounding structures and tissues. It is commonly performed by dentists and oral surgeons in everyday practice and may be used to plan treatment for dentures, braces, extractions, and implants.

If you smoke or vape, seek help to quit

A history of smoking or vaping nicotine increases your chances of developing head and neck, lung, and other cancers. Smoking and vaping can limit how well cancer treatment works and prevent wound healing. They also greatly increase your chances of having side effects during and after surgery. Cannabis use might also affect the amount of anesthesia used during surgery.

Nicotine is the chemical in tobacco that makes you want to keep smoking and vaping. Nicotine withdrawal is challenging for most people who smoke or vape. The stress of having cancer may make it even harder to quit. If you smoke or vape, ask your care team about counseling and medicines to help you quit. In head and neck cancers, stopping smoking or vaping is essential to maximize the chance for cure and minimize side effects.

For online support, try these websites:

- [SmokeFree.gov](https://www.smokefree.gov)
- [BeTobaccoFree.gov](https://www.betobaccofree.gov)
- [CDC.gov/tobacco](https://www.cdc.gov/tobacco)

Biopsy

A biopsy removes a sample of tissue or fluid. Samples removed during a biopsy or surgery will be sent to a pathologist, an expert in examining cells using a microscope (called cytology) to confirm the presence of cancer. The pathologist will determine the cancer subtype called tumor histology.

A fine-needle aspiration (FNA), fine needle biopsy (FNB), and core needle biopsy (CNB) use needles of different sizes to remove a sample of tumor or lymph node. An ultrasound or CT scan might be used to guide a lymph node biopsy.

Biopsy of metastasis

Metastasis is the spread of cancer to an area of the body such as lymph nodes or lung. A biopsy of the metastasis may be needed to confirm the presence of cancer. If there is more than one metastasis, each site may be biopsied. The type of biopsy used depends on the location of the suspected metastases and other factors.

Biomarker testing

Inside our cells are deoxyribonucleic acid (DNA) molecules. These molecules are tightly packaged into what is called a chromosome. Chromosomes contain most of the genetic information in a cell. Normal human cells contain 23 pairs of chromosomes for a total of 46 chromosomes. Each chromosome contains thousands of genes. Genes are coded instructions for the proteins your cells make. Most genes contain information about a specific protein. A mutation is when something goes wrong in the genetic code.

Biomarker tumor testing includes tests of genes or their products (proteins). It identifies the presence or absence of mutations and certain proteins that might suggest treatment. This information may be helpful when choosing the best treatment for you. It is sometimes called molecular testing or tumor profiling, tumor sequencing, gene expression profiling, or genomic testing. These tests are generally used in advanced or widely spread (metastatic) cancers. However, in comparison to other cancers, molecular testing has limited value in the treatment of mouth cancers since there are few drugs that specifically target the genetic mutations causing mouth cancers to grow and spread.

MSI-H/dMMR mutation

Microsatellites are short, repeated strings of DNA. When errors or defects occur, they are fixed by mismatch repair (MMR) proteins. Some cancers have DNA mutations or changes that prevent these errors from being fixed. This is called microsatellite instability (MSI) or deficient mismatch repair (dMMR). When cancer cells have more than a normal

number of microsatellites, it is called MSI-H (microsatellite instability-high). This is often due to dMMR genes.

PD-L1 testing

Programmed death ligand 1 (PD-L1) is an immune protein. If this protein is expressed on the surface of cancer cells, it can cause your immune cells to ignore the cancer and suppress the anti-tumor immune response. This is designed to activate your immune system to better fight off the cancer cells. PD-L1 expression is measured using a combined positive score (CPS), which measures the immune proteins in your tumor and your immune system. If your cancer expresses this protein and has a CPS of at least 1 percent (1%) or higher, you might have treatment that combines chemotherapy and an immune checkpoint inhibitor therapy, or immune checkpoint inhibitor therapy by itself.

Tumor mutational burden

When there are 10 or more mutations per million base pairs of tumor DNA, it is called tumor mutational burden-high (TMB-H). Metastatic or unresectable TMB cancers are often treated using immune checkpoint inhibitors that target the proteins called programmed death protein 1 (PD-1) and programmed death ligand 1 (PD-L1).

Tumor mutation testing

Tumor mutation testing or tumor genomic aberration testing uses a sample of your tumor or blood to see if the cancer cells have any specific DNA mutations. This is a different type of DNA testing than the genetic testing for mutations you may have inherited from your biological parents. In tumor mutation testing, only the tumor is tested and not the rest of your body. Some mutations can be targeted with specific therapies.



If you feel something different around your neck, glands, tongue, or mouth area, please don't wait! Go see an ear, nose, and throat (ENT) doctor."

Key points

- Results from imaging studies and biopsy may help determine your treatment plan. Often, information is collected over time, even as treatment begins. Online portals are a great way to access your test results. Please discuss your results with your health care provider
- A medical history and physical exam inform your care team about your overall health.
- Head and neck cancer and its treatment can affect the health of your jaw, teeth, and gums. Tell your dentist about your head and neck cancer and keep up with regular dental cleanings and checkups.
- Treatment can affect fertility. Talk to your care team about your concerns and if you are planning a pregnancy.
- Imaging tests take pictures of the inside of your body.
- A biopsy removes a sample of tissue or fluid for testing.
- In some cases, a sample of your tumor may be tested to look for specific DNA (deoxyribonucleic acid) mutations, protein levels, or other molecular features. Some mutations and proteins might be targeted with specific therapies.
- Smoking or heavy alcohol use will affect your treatment outcomes and increase treatment toxicity. It is strongly recommended you seek help to stop smoking or vaping.



We want your feedback!

Our goal is to provide helpful and easy-to-understand information on cancer.

Take our survey to let us know what we got right and what we could do better.

[NCCN.org/patients/feedback](https://www.nccn.org/patients/feedback)

3

Mouth cancer staging

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Cancer staging is used to reflect prognosis and to guide treatment decisions. It describes the size and location of the tumor and if cancer has spread to lymph nodes or other parts of the body. This chapter explains mouth cancer stages.

How mouth cancer is staged

A cancer stage is a way to describe the extent of the cancer at the time you are first diagnosed. The American Joint Committee on Cancer (AJCC) created a staging system to determine how much cancer is in your body, where it is located, and what subtype you have. This is called staging.

Based on testing, your cancer will be assigned a stage. Staging helps to predict prognosis and is needed to make treatment decisions. A prognosis is the course your cancer will likely take. AJCC is just one type of staging system.

Information gathered during staging:

- **The extent (size) of the tumor (T):** How large is the cancer? Has it grown into nearby areas?
- **The spread to nearby lymph nodes (N):** Has the cancer spread to nearby lymph nodes? If so, how many? Where?
- **The spread (metastasis) to distant sites (M):** Has the cancer spread to distant organs such as the lungs or liver?
- **Biomarker testing:** Does the cancer have any genes or mutations that might suggest treatment?

Staging is based on a combination of information to reach a final numbered stage. Often, not all information is available at the initial evaluation. More information can be gathered as treatment begins. Doctors may explain your cancer stage in different ways than described next.

Staging includes:

- **Anatomic** – based on extent of cancer as defined by tumor size (T), lymph node status (N), and distant metastasis (M).
- **Prognostic** – includes anatomic TNM. The prognostic stage also includes the assumption that you are treated with the standard-of-care approaches.

Prognostic stages are divided into clinical and pathologic. Cancer staging is often done twice, before and after surgery. Staging after surgery provides more specific and accurate details about the size of the cancer and lymph node status.

Clinical stage

Clinical stage (c) is the rating given before any treatment. It is based on a physical exam, biopsy, and imaging tests. An example might look like cN1 or cM1. In mouth cancer, the clinical stage is based on imaging and biopsy results. These tests are done before any treatment as part of an initial diagnosis.

Pathologic stage

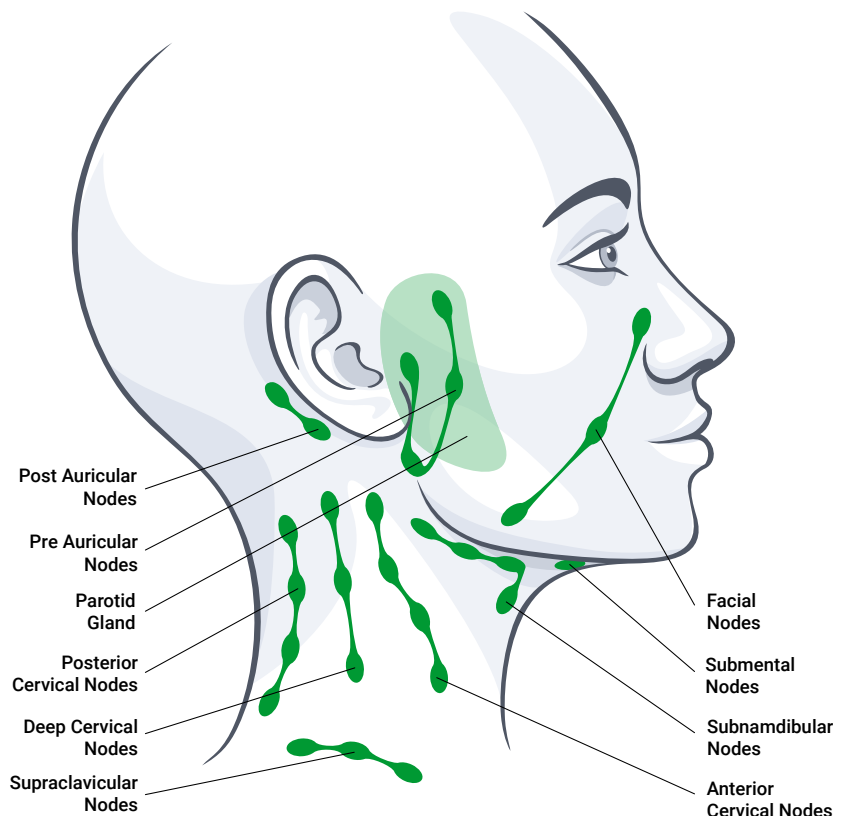
Pathologic stage (p) or surgical stage is determined by examining tissue removed during surgery. An example might be pN2. If you are given cancer drug therapy before surgery, then the stage might add a "y" and look like ypT3.



Anyone can give up; It's the easiest thing in the world to do, but to hold it together when everyone would expect for you to fall apart, now that is true strength."

Lymph nodes in the head and neck

There are over 300 lymph nodes in the head and neck. Most tumors spread to nearby lymph nodes.



TNM scores

The tumor, node, metastasis (TNM) system is used to stage mouth cancer. In this system, the letters T, N, and M describe different areas of cancer growth. Based on imaging and pathology results, a score or number is assigned to each letter. The higher the number, the larger the tumor or the more the cancer has spread. These scores will be combined to assign the cancer a stage. A TNM example might look like this: T1N0M0 or T1, N0, M0.

- **T (tumor)** – Depth and size of the main (primary) tumor and if the tumor has grown into nearby tissue (tumor extension).
- **N (node)** – If cancer has spread to nearby (regional) lymph nodes
- **M (metastasis)** – If cancer has spread to distant parts of the body or metastasized

Numbered stages

Numbered stages are based on TNM scores. Stages range from stage 0 to stage 4, with 4 being the most advanced. They might also be written as stage 0, stage I, stage II, stage III, and stage IV.

Other terms might be used instead of numbered cancer stages.

- **Resectable** – Tumor can be removed completely with surgery.
- **Unresectable** – Tumor cannot be removed completely with surgery. The tumor might involve major vessels or other normal critical structures making it unsafe to remove.

- **Locoregional or locally advanced** – This refers to a tumor that has spread to tissue, organs, or lymph nodes near the mouth.
- **Moderately or very advanced disease** – This includes cancer that has spread to parts of the neck such as the bones and muscles of the jaw, sinuses, or skin. It might include cancer in the base of the skull or carotid artery.
- **Metastatic** – This is cancer that has spread to other parts of the body, including lung and distant lymph nodes. This might be referred to as very advanced disease. Not all stage 4 cancers are metastatic.

Your preferences about treatment are always important. Talk to your care team and make your wishes known.



Mouth cancer stages

The following TNM staging information is used for squamous cell carcinoma (SCC) of the mouth including mucosa of the lip. These are tumors that start in the surface (epithelium), which lines the inside of the mouth. The epithelial layer is made up of squamous cells.

See Guide 2.

T = Tumor

A tumor can grow into nearby structures. Tumor size is measured in centimeters (cm) or millimeters (mm). A golf ball is 4 cm (40 mm) and a pea is 1 cm (10 mm). Depth of invasion (DOI) is a measure of how deep the tumor has grown into the layers of tissue, not tumor thickness. Imaging scans such as an MRI can be used to calculate DOI. As depth of invasion increases, the risk of regional lymph node metastases also increases.

- **Tis** – This is carcinoma in situ, meaning that cancerous cells are found only in the squamous cell layer.
- **T1** – Tumor is 2 cm or less with DOI of 5 mm or less.
- **T2** – Tumor is 2 cm or less with DOI of more than 5 mm or tumor is between 2 cm and 4 cm with DOI of 10 mm or less.
- **T3** – Tumor is between 2 cm and 4 cm with DOI of more than 10 mm or tumor is larger than 4 cm with DOI of 10 mm or less.
- **T4a** – Moderately advanced local disease. Tumor is more than 4 cm with DOI of more than 10 mm or tumor invades nearby structures only, such as through the cortical bone of the mandible

or maxilla or involves the maxillary sinus or skin of the face.

- **T4b** – Very advanced local disease. Tumor has invaded the masticator space, pterygoid plates, or skull base and/or encases the internal carotid artery.

N = Regional lymph node

There are hundreds of lymph nodes throughout your body. They work as filters to help fight infection and remove harmful things from your body. The head and neck contain a network of more than 300 nodes. They are bound together with muscles, nerves, and blood and lymph vessels. Head and neck cancers sometimes spread to neck lymph nodes. Regional lymph nodes are found near

Guide 2 Mouth cancer stages

Stage 0	• Tis, N0, M0
Stage 1	• T1, N0, M0
Stage 2	• T2, N0 or N1, M0
Stage 3	• T1 or T2, N1, M0 • T3, N0 or N1, M0
Stage 4A	• T1 or T2 or T3, N2, M0 • T4a, N1 or N2 or N3, M0
Stage 4B	• Any T, N3, M0 • T4b, Any N, M0
Stage 4C	• Any T, Any N, M1

the tumor. Cancer found in a regional lymph node is a lymph node metastasis. This is different than a distant metastasis, which is found outside the neck. When cancer has grown through and spreads outside of the lymph node, it is referred to as extranodal extension or extranodal extension-positive (ENE+).

Clinical N

- **N0** – No regional lymph node metastasis is found.
- **N1** – One lymph node with metastasis 3 cm or smaller is found on the same side (ipsilateral) as the tumor. Cancer is not found outside of the lymph node (ENE-).
- **N2a** – One lymph node with metastasis between 3 cm and 6 cm is found on the same side (ipsilateral) as the tumor and ENE-.
- **N2b** – Metastases are found in multiple ipsilateral lymph nodes. None larger than 6 cm and ENE-.
- **N2c** – Lymph nodes with metastasis are found on the opposite side (contralateral) as the tumor or on both sides (bilateral), none larger than 6 cm. ENE-.
- **N3a** – Lymph node metastasis is larger than 6 cm and ENE-.
- **N3b** – Metastasis in any lymph node(s) and ENE+.

Pathologic N

- **pN0** – No regional lymph node metastasis is found.
- **pN1** – One lymph node with metastasis 3 cm or smaller is found on the same side (ipsilateral) as the tumor and ENE-.
- **pN2a** – One lymph node with metastasis 3 cm or smaller is found on the same side (ipsilateral) as the tumor and ENE+.
- **pN2b** – Metastases are found in multiple ipsilateral lymph nodes. None are larger than 6 cm and ENE-.
- **pN2c** – Lymph nodes with metastasis are found on the opposite side (contralateral) as the tumor or on both sides (bilateral), none larger than 6 cm and ENE-.
- **pN3a** – Lymph node metastasis is larger than 6 cm and ENE-.
- **pN3b** – Lymph node metastasis is larger than 6 cm and ENE+ or metastases are found in multiple lymph nodes and ENE+ or metastasis found in 1 lymph node on the opposite side (contralateral) of the tumor and ENE+.

M = Metastasis

Cancer that has spread to distant parts of the body through the bloodstream is shown as M1. The most common site for metastasis is the lymph nodes outside the head and neck, lungs, or bones.

Key points

- A cancer stage helps to predict the likely course your cancer will take, called a prognosis. It describes the size and location of the tumor and if cancer has spread to lymph nodes, organs, or other parts of the body.
- Staging is only one part of treatment decision-making.
- The head and neck contain a network of more than 300 lymph nodes, connected by lymph channels, which drain all areas of the head and neck.
- Head and neck cancer can sometimes spread to neck (cervical) lymph nodes.
- Not all stage 4 mouth cancers have distant metastases.

Everyone with head and neck cancer should meet with an otolaryngologist, head and neck surgeon, or surgical oncologist who is an expert in head and neck cancer before starting treatment.

4

Treating mouth cancer

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- 28 Surgery
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- 34 Systemic therapy
- 35 Clinical trials
- 37 Supportive care
- 38 Side effects
- 41 Key points

This chapter describes an overview of treatment options and what to expect. Together, you and your care team will choose a treatment plan that is best for you.

Care team

Those with head and neck cancer should seek treatment at experienced cancer centers.

Treating cancer takes a team approach. Treatment decisions should involve a multidisciplinary team (MDT). An MDT is a team of health care and psychosocial care professionals from different professional backgrounds who have knowledge (expertise) and experience in your type of cancer. This team is united in the planning and implementation of your treatment. Ask who will coordinate your care.

Some members of your care team will be with you throughout cancer treatment, while others will only be there for parts of it. Get to know your care team and help them get to know you.

Depending on your diagnosis, your team might include the following specialists:

- **An otolaryngologist** is an expert in the ear, nose, and throat (ENT).
- **A dentist** diagnoses and treats oral health conditions. You might need to see a dentist more often during treatment. Tell your dentist as soon as you know about your cancer diagnosis.

- **An otolaryngologist, head and neck surgeon, or surgical oncologist** can perform operations to remove cancer in the mouth.
- **An oral maxillofacial surgeon (OMFS)** is a special type of dentist trained to recognize and treat diseases and injuries in the head, neck, face, jaws, and mouth.
- **A plastic or reconstruction surgeon** can repair areas removed during surgery.
- **Oncologists** specialize in diagnosing and treating cancer. Types of oncologists include dental, medical, radiation, and surgical oncologists.
- **Oncology nurses** provide your hands-on care, like giving systemic therapy, managing your care, answering questions, and helping you cope with side effects.
- **Oncology pharmacists** are experts in knowing how to use medicines to treat cancer and to manage symptoms and side effects.
- **Palliative care specialists** concentrate on preventing and alleviating suffering and improving quality of life.
- **Radiation therapists** provide your hands-on delivery of radiotherapy treatments.
- **Nutritionists and dietitians** can provide guidance on what foods are most suitable for your condition.
- **An occupational therapist** helps people with the tasks of daily living.
- **A physical therapist** helps people move with greater comfort and ease.

- **A certified lymphedema therapist** gives a type of massage called manual lymph drainage.
- **Speech-language and swallowing therapists** help people who have trouble speaking or swallowing.
- **Psychologists and psychiatrists** are mental health experts who can help manage issues such as depression, anxiety, or other mental health conditions that can affect how you think and feel.
- **Social workers** help people solve and cope with problems in their everyday lives. Clinical social workers also diagnose and treat mental, behavioral, and emotional issues. The anxiety a person feels when diagnosed with cancer might be managed by a social worker in some cancer centers. They, or other designated professionals, can help navigate the complexities of financial and insurance stresses.
- **Spiritual care specialists** identify and support those with spiritual distress or unmet spiritual needs.
- **Smoking cessation specialists** can provide medication and counseling for those who would like to stop using tobacco or nicotine products.
- **A research team** helps to collect research data and coordinate care if you are in a clinical trial. Clinical trials help bring new therapies to patients and advance the treatment for everyone. Consider asking your care team about access to clinical trials.

Surgery

Surgery is an operation or procedure to remove cancer from the body. When preparing for surgery, you should seek the opinion of an experienced otolaryngologist, head and neck surgeon, or surgical oncologist with expertise in head and neck cancer. The surgeon should be an expert in performing your type of surgery. Hospitals that perform many surgeries often have better results. You can ask for a referral to a hospital or cancer center that has experience in treating your type of cancer.

The removal of the cancer through surgery can be accomplished in different ways depending on the specific circumstances, such as the size and location of the tumor, whether there is cancer in any surrounding organs and tissues, and your unique anatomy. Surgery is based on the safest and best way to remove cancer.

When planning for surgery, you should ask how your breathing, swallowing, speaking, chewing, and appearance might be affected. Sometimes nerves might need to be cut and sewn back together or removed as part of cancer surgery. Lymph nodes are often removed. This is the time to ask how your neck and face might look after surgery and your options about facial reconstruction surgery.

Goal of surgery

The goal of surgery is to remove all of the cancer and keep your ability to function, such as chew, swallow, breathe, and speak. During surgery, the tumor is removed along with a rim of normal-looking tissue around its edge called the surgical margin. The surgical margin may look normal but cancerous cells may be found when viewed under a microscope by a

pathologist. A clear or negative margin (R0) is when no cancer cells are found in the tissue around the edge of the tumor. In a positive margin, cancer cells are found in normal-looking tissue around the tumor. Your surgeon will look carefully for cancer not only along the surgical margin, but in other nearby areas. Despite best efforts, it is not always possible to find all of the cancer. Sometimes, surgeons can't safely remove the tumor with a cancer-free margin. Surgery often includes removal of lymph nodes. You may have more than one surgery. Surgery may also include rebuilding or reconstructing any tissues that may have been removed.

After surgery, you may receive treatment such as radiation or chemotherapy with radiation (chemoradiation) to kill any remaining cancer cells.

Tumor resection

Surgery to remove the entire tumor is called tumor resection. Sometimes, the whole tumor cannot be removed. It depends on the tumor location, what structures are involved, how close it is to vital organs, the depth of invasion (DOI), and how function (such as swallowing and speaking) will be affected. The removal of lymph nodes is often part of cancer surgery. For mouth cancers, as depth of invasion increases, the risk of regional lymph node metastases and the need for lymph node surgery (neck dissection) also increases.

Reconstruction after tumor removal

If you plan to have reconstruction surgery after tumor resection, you want to ask questions now. For example, a multidisciplinary team



You know your body better than anyone

Help your care team understand:

- ✓ How you feel
- ✓ What you need
- ✓ What is working and what is not

Keep a list of names and contact information for each member of your team. This will make it easier for you and anyone involved in your care to know whom to contact with questions or concerns.

Get to know your care team and help them get to know you.

(MDT) is needed to perform high-quality reconstruction. Find out who will be on the reconstruction team. A MDT team is critical to your functional and cosmetic recovery. Make it a priority to ask your surgeons if they will remove tissue from one part of your body to repair or reconstruct areas of the mouth or throat. Also, ask the expected length of the surgery (time spent in the operating room) and recovery. You may stay in a special nursing area ("flap unit") in the hospital to make sure you recover safely. The more information you have, the better prepared you will be.

Neck lymph nodes

There are hundreds of lymph nodes throughout your body. They work as filters to help fight infection and remove harmful things from your body. Lymph is a clear fluid that gives cells water and food. It also helps to fight germs. Lymph drains from lymph tissue and travels through lymphatic vessels into lymph nodes.

The head and neck contain a network of more than 300 nodes. They are bound together with muscles, nerves, and blood and lymph vessels. Cancer can spread into these areas and nearby lymph nodes. Mouth cancer often spreads to lymph nodes or lymph node groups called chains.

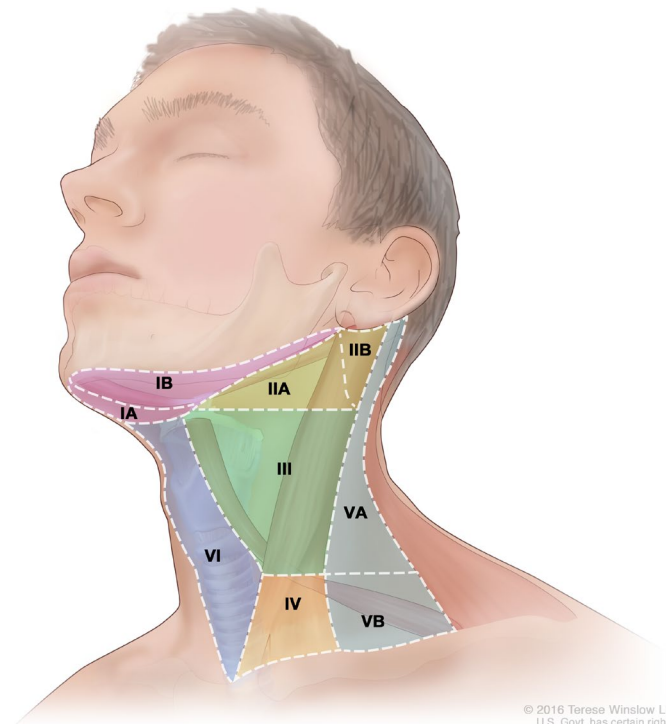
Cervical lymph nodes are found only in the neck. The 6 (VI) levels for neck lymph node

groups are described below. Lymph nodes from levels 1, 2, and 3 are at the greatest risk for mouth cancer metastasis.

- ▶ **Level 1 (I)** – Submental and Submandibular Group (under the jaw line)
 - 1A – Submental nodes
 - 1B – Submandibular nodes
 - 1A and 1B are separated by the front part of a neck muscle (digastric muscle)
- ▶ **Level 2 (II)** – Upper Jugular Group (the upper neck)
 - 2A and 2B are separated by the spinal accessory nerve
- ▶ **Level 3 (III)** – Middle Jugular Group (the middle neck)

Neck lymph node groups or levels

Cervical lymph nodes are found only in the neck. The 6 (VI) levels for neck lymph node groups are pictured on the right. Lymph nodes from levels 1, 2, and 3 are at the greatest risk for mouth cancer metastasis.



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- **Level 4 (IV)** – Lower Jugular Group (the lower neck)
- **Level 5 (V)** – Posterior Triangle Group (the back portion of the neck)
 - 5A superior half (toward the head)
 - 5B inferior half (away from the head)
- **Level 6 (VI)** – Central (Anterior) Compartment Group (near the windpipe)

Lymph node surgery

The removal of lymph nodes or groups of lymph nodes is called lymph node or nodal dissection. It might be referred to as cervical lymphadenectomy or neck dissection and is often part of tumor resection surgery. Lymph nodes may be removed on the side of the neck where the main (primary) tumor is found. When the tumor is near the center of the neck (midline), then lymph nodes from both sides may be removed. The type of neck dissection is based on tumor location and information gathered in the pre-surgery (clinical) staging.

There are different types of cervical (neck) lymph node dissections:

- **Selective neck dissection (SND)** removes some of the regional lymph nodes where the cancer is likely to travel.
- **Comprehensive neck dissection** removes all lymph nodes in a group or level.
- **Radical neck dissection** removes all lymph nodes, and may require removing veins, arteries, nerves, or muscle next to the nodes.
- **Sentinel lymph node biopsy** is done during surgery to remove the tumor.

Sentinel lymph node biopsy

A sentinel lymph node (SLN) is the first lymph node that cancer cells are most likely to spread to from a primary tumor. Sometimes, there can be more than one sentinel lymph node. Removal of the sentinel lymph nodes during surgery is called a sentinel lymph node biopsy (SLNB or SNB). It is done to determine if any cancer cells have traveled to the lymph nodes. The lymph nodes removed are called the sentinel nodes. They may or may not contain any cancer cells. Just because these nodes are removed, it does not mean that they are positive for cancer.

To find the sentinel lymph nodes, a radioactive material and other dyes are injected into the area where tumor is located. From here, the dye travels through the lymphatic system to the lymph nodes. Once the nodes are found, those containing the radioactive material or dye are removed and tested by a pathologist. If cancer is found, then further treatment may be needed.

Radiation therapy

Radiation therapy (RT) uses high-energy radiation from x-rays, photons, electrons, and other sources to kill cancer cells and shrink tumors. RT may be used as the main treatment to cure cancer (curative treatment), or as supportive care or palliative care to help ease pain or discomfort caused by advanced cancer.

Radiation is typically delivered from outside the body by a computerized device, which can shape to the treatment to closely fit your body. Treatment is given in small daily doses, typically over 6 to 7 weeks on workdays, with weekends off. In special circumstances, particularly for palliative treatment, your course of therapy may be shorter. A device resembling a hockey goalie mask may be used to keep you still during treatment. If you get uncomfortable in tight spaces, please talk to

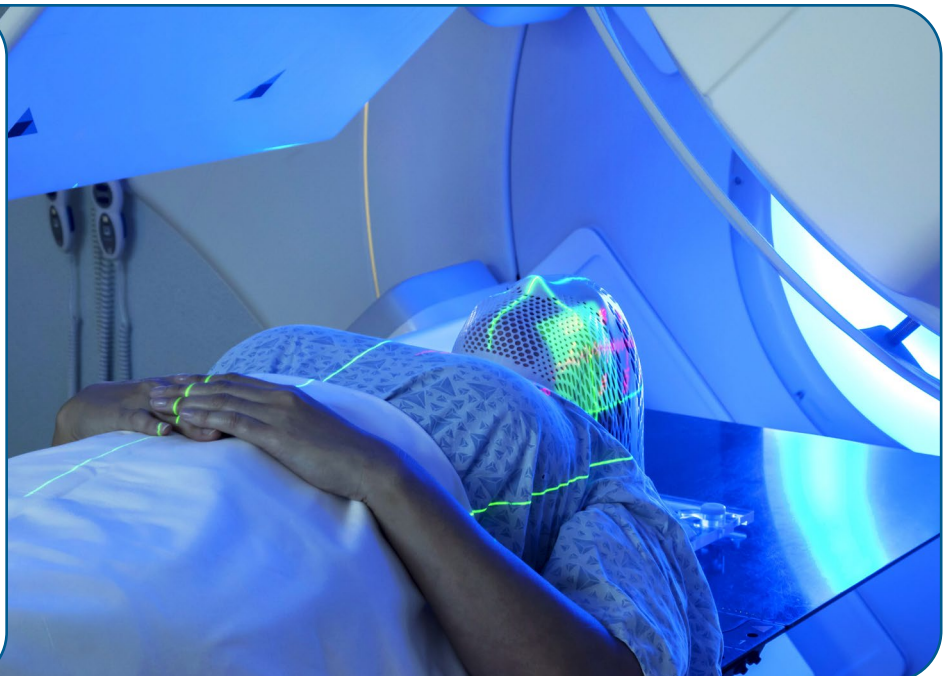
your radiation oncologist for ways to help keep you comfortable and calm.

You will see your radiation oncology at least weekly to review your progress and to help with side effects, such as sunburn-like rash, mouth soreness, lack of taste, dry mouth, or thick saliva. Ask your care team which radiation option(s) are best for your situation, if RT will be combined with chemotherapy, and what side effects to expect. RT puts you at a small risk of developing another cancer in the future.

Panoramic dental x-ray is part of a pre-radiation therapy dental evaluation. It is needed to check the health of your jaw and teeth to see if you need any dental work before starting RT. It is important to tell your dentist about your head and neck cancer and to have regular dental cleanings and checkups.

Radiation therapy

External beam radiation therapy (EBRT) uses a machine outside the body to aim radiation at the tumor(s) or areas of the body.



External beam radiation

External beam radiation therapy (EBRT) uses a machine outside the body to aim radiation at the tumor(s) or areas of the body.

Common types of EBRT that may be used to treat your cancer include the following:

- **Three-dimensional conformal radiation therapy (3D-CRT)** uses computer software and CT images to aim beams that match the shape of the tumor.
- **Intensity-modulated radiation therapy (IMRT)** uses small beams of different strengths to match the shape of the tumor. This limits the amount of radiation to normal tissue.
- **Stereotactic body radiation therapy (SBRT)** uses high-energy proton or photon beams to kill or ablate the tumor. SBRT is very precise, which reduces the chance of damage to nearby tissues.
- **Proton beam therapy (PBT)** uses proton beams to kill or ablate the tumor. It might be used for a lesion near the skull base, brain stem, optical nerve, or spinal cord; or to preserve parotid function.

Either IMRT (preferred) or 3D-CRT is recommended for mouth cancer to minimize radiation dose to critical structures.

Internal radiation

Internal radiation (brachytherapy) involves placing one or more small tubes into the tumor area. A small radioactive seed travels into the tube(s) and delivers radiation to the tumor area from inside the body.



Finding a clinical trial

In the United States

NCCN Cancer Centers
[NCCN.org/cancercenters](https://www.nccn.org/cancercenters)

The National Cancer Institute (NCI)
[cancer.gov/about-cancer/treatment/clinical-trials/search](https://www.cancer.gov/about-cancer/treatment/clinical-trials/search)

Worldwide

The U.S. National Library of Medicine (NLM)
clinicaltrials.gov

Need help finding a clinical trial?

NCI's Cancer Information Service (CIS)
 1.800.4.CANCER (1.800.422.6237)
[cancer.gov/contact](https://www.cancer.gov/contact)

Systemic therapy

Systemic therapy works throughout the body. Types include chemotherapy, targeted therapy, and immunotherapy. Systemic therapy might be used alone or with other therapies. Goals of systemic therapy may be curative or palliative and should be discussed before starting treatment. The choice of systemic therapy will be based on your individual needs. Your wishes about treatment are important. Make your wishes known.

- ▶ When systemic therapy is given before surgery or chemoradiation, it is called **neoadjuvant or induction therapy**.
- ▶ When systemic therapy, chemoradiation, or radiation therapy is given after surgery, it is called **adjuvant or postoperative therapy**.
- ▶ When systemic therapy is given for noncurable advanced or metastatic disease, it is called **palliative therapy**.

For systemic therapy examples, **see Guide 3**.

Chemotherapy

Chemotherapy kills fast-dividing cells throughout the body, including cancer cells and some normal cells. Sometimes, chemotherapies are combined together, or are combined with a checkpoint inhibitor therapy or targeted therapy. This is called multiagent chemotherapy. Chemotherapy might be followed by radiation therapy or chemoradiation.

Chemoradiation

Treatment that combines chemotherapy with radiation therapy is called chemoradiation. Chemotherapy may improve how well radiation works; that is why they are sometimes used together. For locally advanced disease, cisplatin is often the preferred chemotherapy drug given with radiation therapy (RT). Chemoradiation is often used to cure your cancer. Chemoradiation may also be used to control symptoms caused by a tumor even if a cure is not possible.

Guide 3 Systemic therapy examples

Chemotherapy examples	<ul style="list-style-type: none"> • Capecitabine (Xeloda) • Carboplatin • Cisplatin • Docetaxel (Taxotere) • 5-Fluorouracil (5-FU) 	<ul style="list-style-type: none"> • Hydroxyurea (Hydrea) • Methotrexate • Paclitaxel (Taxol) • Pemetrexed (Alimta)
Targeted therapy examples	<ul style="list-style-type: none"> • Afatinib (Gilotrif) • Cetuximab (Erbix) 	
Immunotherapy examples	<ul style="list-style-type: none"> • Ipilimumab (Yervoy) • Nivolumab (Opdivo) • Pembrolizumab (Keytruda) 	

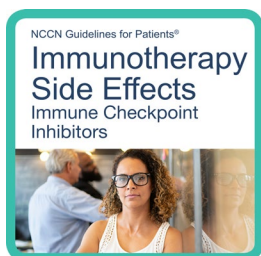
Targeted therapy

Targeted therapy focuses on specific or unique features of cancer cells. Targeted therapies seek out how cancer cells grow, divide, and move in the body. These drugs stop or inhibit the action of molecules that help cancer cells grow and/or survive. If your tumor has certain mutations, targeted therapy might be used.

Immunotherapy

Immunotherapy is a type of systemic treatment that tries to reactivate the immune system against tumor cells. The immune system has many on and off switches. Tumors take advantage of turning on the "off switches." If your tumor has a high number of mutations, immunotherapy might be given. Immunotherapy can be given alone or with chemotherapy or targeted therapy.

For more information, see NCCN Guidelines for Patients: Immunotherapy Side Effects, available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.



Clinical trials

A clinical trial is a type of medical research study. After being developed and tested in a laboratory, potential new ways of treating cancer need to be studied in people. If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. Food and Drug Administration (FDA).

Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

Phases

Most cancer clinical trials focus on treatment. Treatment trials are done in phases.

- **Phase I trials** study the dose, safety, and side effects of an investigational drug or treatment approach. They also look for early signs that the drug or approach is helpful.
- **Phase II trials** study how well the drug or approach works against a specific type of cancer.
- **Phase III trials** test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- **Phase IV trials** study the long-term safety and benefit of an FDA-approved treatment.

Who can enroll?

Every clinical trial has rules for joining, called eligibility criteria. The rules may be about age, cancer type and stage, treatment history, lab tests, or general health. These requirements ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.

Informed consent

Clinical trials are managed by a group of experts called a research team. The research team will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also provided in an informed consent form. Read the form carefully and ask questions before signing it. Take time to discuss with family, friends, or others whom you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time.

Start the conversation

Don't wait for your doctor to bring up clinical trials. Start the conversation and learn about all of your treatment options. If you find a study that you may be eligible for, ask your treatment team if you meet the requirements. If you have already started standard treatment you may not be eligible for certain clinical trials. Try not to be discouraged if you cannot join. New clinical trials are always becoming available.

Frequently asked questions

There are many myths and misconceptions surrounding clinical trials. The possible benefits and risks are not well understood by many with cancer.

Will I get a placebo?

Placebos (inactive versions of real medicines) are almost never used alone in cancer clinical trials. It is common to receive either a placebo with a standard treatment, or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Do I have to pay to be in a clinical trial?

It depends on the study, your health insurance, and the state in which you live. In general, procedures, drugs, or tests that are considered standard of care will be billed to you or your insurance, whereas those considered research are covered by the trial sponsor. Your treatment team and the research team can help determine if you are responsible for any costs.

Supportive care

Supportive care will be specific to your needs. Supportive care is health care given to prevent, reduce, and relieve suffering, and to improve quality of life. Supportive care might include pain relief, palliative care, emotional or spiritual support, financial aid, or family counseling. Tell your care team how you are feeling and about any side effects so they can be managed. Supportive care, best supportive care, and palliative care often mean the same thing.

It is very important to take care of yourself by eating well, drinking plenty of fluids, exercising, and doing things that make you feel energized. Strength is needed to sustain you during treatment.

Side effects

All cancer treatments can cause unwanted health issues called side effects. Side effects depend on many factors. These factors include the drug type and dose, length of treatment, and the person. Some side effects may be harmful to your health. Others may just be unpleasant. Treatment can cause several side effects. Some are very serious.

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

It is important to tell your care team about all of your side effects so they can be managed.

Late effects

Late effects are side effects that occur months or years after a disease is diagnosed or after treatment has ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental, and social problems, and second cancers. The sooner late effects are treated the better. Ask your care team about what late effects could occur. This will help you know what to look for.

Survivorship

A person is a cancer survivor from the time of diagnosis until the end of life. When treatment leads to remission (or no evidence of disease), you will need follow-up or survivorship care for late effects. During survivorship care you will still have a care team, but it will look different. Seek out peer support groups, whether online or in person.

Side effects

Difficulty eating, swallowing, or speaking

Because of the location of mouth cancer, difficulty eating, swallowing, or speaking are common side effects of treatment. Difficulty swallowing (dysphagia) or painful swallowing (odynophagia) can be caused by cancer or its treatment and might be long term (chronic). Speech-language pathologists (SLPs) can help people who have trouble swallowing or speaking.

Lymphedema

Lymphedema is a condition in which lymph fluid builds up in tissues and causes swelling. It may be caused when part of the lymph system is damaged or blocked, such as during surgery to remove lymph nodes, or by radiation therapy. Cancers that block lymph vessels can also cause lymphedema. Swelling usually develops slowly over time. It may develop during treatment, or it may start years after treatment. If you have lymphedema, you may be referred to an expert in lymphedema management. The swelling may be reduced by exercise, massage, compression devices, and other means.

Pain

Tell your care team about any pain or discomfort. You might meet with a palliative care specialist or with a pain specialist to manage pain. Some people may benefit from palliative radiation therapy or ablation therapy to help relieve pain. During this treatment, a radiation beam is focused on the tumor.

Cranial neuropathies

Cranial neuropathy affects the nerves in the head and neck and might cause pain; dizziness (vertigo); weakness, numbness, or tingling in the face; or changes in vision, hearing, taste, and smell. These changes can affect speech, swallowing, and hearing, making it difficult to communicate. This might cause distress and impact your ability to function and complete certain tasks at home and at work. Your treatment may not completely reverse these symptoms. Treatment may also worsen or cause new cranial neuropathies if your cancer is located close to sensitive nerve or brain structures. Ask your doctor about these risks, and what can be done to minimize them. You can also ask to see an occupational therapist or speech-language pathologist (SLP), who might be able to help your recovery from these symptoms.

Distress

Depression, anxiety, and sleeping issues are common and are a normal part of cancer diagnosis. Talk to your care team and with those whom you feel most comfortable about how you are feeling. There are services, people, and medicines that can help you. Support and counseling services are available.

Dry mouth

Xerostomia is the medical term for dry mouth. Treatment for mouth cancer can affect your salivary glands. This means you may not make as much spit (saliva) as before and so your mouth may become dry. It is a very common side effect after radiation and might be long term (chronic). Drinking plenty of water and avoiding beverages with caffeine, alcohol,

or sugar can help. Special mouth rinses are available. Continue to see your dentist regularly.

Fatigue

Fatigue is extreme tiredness and inability to function due to lack of energy. Fatigue may be caused by cancer or it may be a side effect of treatment. Let your care team know how you are feeling and if fatigue is getting in the way of doing the things you enjoy. Eating a balanced diet, exercise, yoga, acupuncture, and massage therapy can help. You might be referred to a nutritionist or dietitian to help with fatigue.

Loss of appetite

Sometimes side effects from cancer or its treatment, and the stress of having cancer might cause you to feel not hungry or sick to your stomach (nauseated). You might have a sore mouth or difficulty swallowing. Healthy eating is important during treatment. It includes eating a balanced diet, eating the right amount of food, and drinking enough fluids. A registered dietitian who is an expert in nutrition and food can help. Weight loss is common in those with head and neck cancer. You might be asked to see a nutrition expert before starting treatment to help prevent severe weight loss.

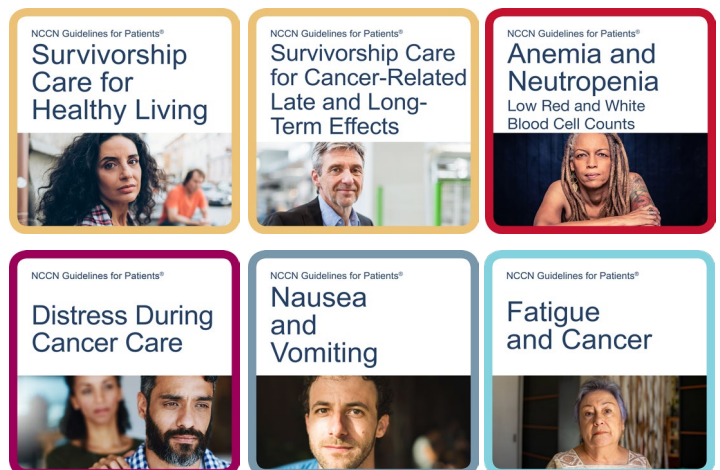
Low blood cell counts

Some cancer treatments can cause low blood cell counts.

- **Anemia** is a condition where your body does not have enough healthy blood cells, resulting in less oxygen being carried to your cells. You might tire easily if you are anemic.
- **Neutropenia** is a decrease in neutrophils, a type of white blood cell. This puts you at risk for infection.
- **Thrombocytopenia** is a condition where there are not enough platelets found in the blood. This puts you at risk for bleeding.

Supportive care resources

More information on supportive care is available at: [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.



Nausea and vomiting

Nausea and vomiting are common side effects of treatment. You will be given medicine to prevent nausea and vomiting.

Neurocognitive or neuropsychological effects

Some treatments can damage the nervous system (neurotoxicity) causing problems with concentration, memory, and thinking.

Neuropathy

Neuropathy is a nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. It usually begins in the hands or feet and gets worse over time. Neuropathy may be caused by cancer or cancer treatment. Most of the time, neuropathy goes away after treatment.

Organ issues

Treatment might cause your kidneys to not work as well as they should.

Quality of life

Cancer and its treatment can affect your overall well-being or quality of life (QOL). Head and neck tumors often impact a person's ability to function such as chew, swallow, speak, and breathe. It can also impact taste, smell, hearing, and how your voice sounds or how you look. It is very important that you are well-prepared and understand how surgery or radiation therapy might cause changes to these functions and your appearance. For more information on quality of life, see NCCN Guidelines for Patients: Palliative Care at



Keep a pain diary

A pain diary is a written record that helps you keep track of when you have pain, how bad it is, what causes it, and what makes it better or worse. Use a pain diary to discuss your pain with your care team. You might be referred to a specialist for pain management.

Include in your pain diary:

- ✓ The time and dose of all medicines
- ✓ When pain starts and ends or lessens
- ✓ Where you feel pain
- ✓ A description of your pain. Is it throbbing, sharp, tingling, shooting, or burning? Is it constant, or does it come and go?
- ✓ Does the pain change at different times of day? When?
- ✓ Does the pain get worse before or after meals? Does certain food or drink make it better?
- ✓ Does the pain get better or worse with activity? What kind of activity?
- ✓ Does the pain keep you from falling asleep at night? Does pain wake you up in the night?
- ✓ A rating of your pain from 0 (no pain) to 10 (worst pain you have ever felt)
- ✓ Does pain get in the way of you doing the things you enjoy?

[NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.



Stiff neck

Cancer or its treatment can cause a stiff neck and shoulders and long-term (chronic) neck pain. The stress of having cancer can also cause tightness in the neck, shoulders, jaw, and head. Movement such as tai chi, walking, or stretching, and massage might help a stiff neck and shoulders to feel better. Speak to your care team about how to manage chronic neck pain.

Difficulty with smell, nose bleeds, and congestion

Your sense of smell might be affected by the cancer or its treatment. The lining of your nasal cavity and sinuses might become inflamed or irritated causing your nose to feel stuffed-up or congested. Your nose might bleed. You might have headaches. Your care team might recommend using a humidifier or other ways to help with sinus or nasal irritation.

Key points

- Systemic therapy works throughout the body. It includes chemotherapy, targeted therapy, and immunotherapy.
- Targeted therapies can block the ways cancer cells grow, divide, and move in the body.
- Immunotherapy uses your body's natural defenses to find and destroy cancer cells.
- Radiation therapy (RT) uses high-energy radiation from x-rays, gamma rays, protons, photons, and other sources to kill cancer cells and shrink tumors.
- Treatment that combines chemotherapy with radiation therapy is called chemoradiation.
- A clinical trial is a type of research that studies a treatment to see how safe it is and how well it works.
- Supportive care is health care that relieves symptoms caused by cancer or its treatment and improves quality of life. Supportive care is always given.
- All cancer treatments can cause unwanted health issues called side effects. It is important for you to tell your care team about all your side effects so they can be managed.
- Eating a balanced diet, drinking enough fluids, exercise, yoga, and massage therapy can help manage side effects.
- Pain may be treated with medication, or radiation with or without systemic therapy. Keeping a pain diary might help you manage pain.

5

Early and locally advanced disease

- 43 Early stage
- 44 Locally advanced
- 44 Follow-up care
- 45 Key points

Treatment is based on tumor location and extension and if any lymph nodes have cancer. Surgery is the preferred treatment for early and locally advanced disease. Treatment such as radiation therapy, systemic therapy with radiation therapy (chemoradiation) might follow surgery. Together, you and your care team will choose a treatment plan that is best for you.

Factors such as your overall health are considered when making treatment decisions. Your preferences about treatment are always important. Talk to your care team and make your wishes known.

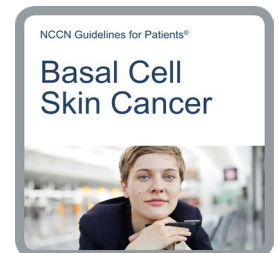
Early stage

In early-stage (stage 1 or 2) cancer, the tumor is less than 4 cm with depth of invasion (DOI) of 10 mm or less. Cancer is not seen in lymph nodes on imaging tests but may be found during a biopsy or lymph node surgery called neck dissection.

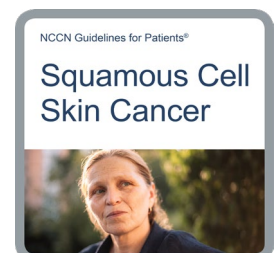
Treatment options include:

- Surgery (preferred) to remove the tumor called tumor resection. Depending on the tumor location, depth of invasion, and imaging test results, lymph nodes might be removed (called neck dissection). A sentinel lymph node (SLN) biopsy might be done before a neck dissection.
- Radiation therapy (RT)
- If cancer is found in lymph nodes after neck dissection or sentinel node biopsy, then treatment might be more surgery, systemic therapy with RT (chemoradiation), or RT alone. The preferred time between resection and postoperative RT is 6 weeks or less.

T1 or T2 simple outer lip lesions are treated as non-melanoma skin cancers with surgery. RT may be added based on surgical pathology findings. More information on non-melanoma skin cancers can be found at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](https://www.nccn.org/patientguidelines) app.



The vermillion lip is the area where the skin and the lip meet on the outside of the mouth. Information for treatment of cutaneous squamous cell carcinoma of the vermillion lip can be found in NCCN Guidelines for Patients: Squamous Cell Skin Cancer at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](https://www.nccn.org/patientguidelines) app.



Locally advanced

In locally advanced (stage 3 or 4a) cancer, the tumor can be any size and may have spread to nearby structures. Cancer metastasis is found in 1 or more lymph nodes and may have grown (extended) outside the lymph node(s). Cancer has not spread through the bloodstream to lymph nodes outside the neck area or distant areas in the body.

Treatment options include:

- Surgery (preferred) to remove the tumor and lymph nodes (called tumor resection and neck dissection). Radiation therapy (RT) or chemoradiation might follow

surgery. The preferred time between resection and postoperative RT is 6 weeks or less.

- Clinical trial

Follow-up care

After treatment, you will be monitored for side effects and for any signs of cancer returning (called recurrence). General follow-up care includes regular and frequent doctor visits to check for late effects and signs that cancer has returned. It is important to contact your doctor right away if you notice any changes in your

Guide 4 Follow-up care

Medical history and physical exam, including complete head and neck exam:

- Year 1, every 1 to 3 months
- Year 2, every 2 to 6 months
- Years 3 through 5, every 4 to 8 months
- Over 5 years, every 12 months

Blood tests to look for hormone levels made by glands in the head and neck

Imaging tests

Dental exam for areas exposed to radiation treatment

Supportive care, as needed:

- Speech, hearing, and swallowing evaluation and rehabilitation
- Nutrition evaluation and rehabilitation
- Ongoing screening for depression
- Help to quit smoking; tobacco use and alcohol use counseling
- Lymphedema evaluation and rehabilitation

Information on survivorship care and creation of a survivorship care plan within 1 year of completing treatment.

head or neck. For general follow-up care, **see Guide 4.**

Key points

- In early-stage cancer, the tumor might be found only in the mouth or in nearby structures.
- Surgery is the preferred treatment for early-stage cancer. Radiation therapy (RT) is also an option.
- Cancer found in lymph nodes might be treated with a combination of surgery, systemic therapy with RT (chemoradiation), or RT alone.
- In locally advanced (stage 3 or 4a) cancer, the tumor can be any size and may have spread to nearby structures. Cancer metastasis may be found in 1 or more lymph nodes and may have grown (extended) outside the lymph node(s).
- Surgery is the preferred treatment for locally advanced cancer. A clinical trial is also an option.
- Treatment such as radiation therapy or chemoradiation might follow surgery.
- After completing treatment, you will have blood and imaging tests, physical exams, and doctor appointments to monitor for any signs of cancer returning. Contact your doctor right away if you notice any changes in your head or neck.



Warnings about supplements and drug interactions

You might be asked to stop taking or avoid certain herbal supplements when on a systemic therapy. Some supplements can affect the ability of a drug to do its job. This is called a drug interaction.

It is critical to speak with your care team about any supplements you may be taking. Some examples include:

- Turmeric
- Ginkgo biloba
- Green tea extract
- St. John's Wort
- Antioxidants

Certain medicines can also affect the ability of a drug to do its job. Antacids, heart or blood pressure medicine, and antidepressants are just some of the medicines that might interact with a systemic therapy or supportive care medicines given during systemic therapy. Therefore, it is very important to tell your care team about any medicines, vitamins, over-the-counter (OTC) drugs, herbals, or supplements you are taking.

Bring a list with you to every visit.

6

Advanced cancer

- 47 Unresectable
- 49 Recurrent or persistent disease
- 49 Metastatic disease
- 50 Key points

Advanced mouth cancer is sometimes also called very advanced cancer. This is cancer that remains after treatment (persistent cancer) or cancer that has returned after a disease-free period (recurrence). It also includes cancer that cannot be removed with surgery (unresectable) or cancer that has spread to near (locoregional) or distant (metastatic) sites through the bloodstream. Together, you and your care team will choose a treatment plan that is best for you.

Tumor mutation or biomarker testing might be done before starting treatment for advanced or very advanced cancer. Ask how treatment will impact the quality of your life and if the goal is to cure or prevent the further spread of cancer.

Unresectable

An unresectable tumor cannot be removed with surgery. Sometimes, it is unsafe to remove the tumor with surgery because it is too close to vital organs. You may not want surgery. You may have other health conditions that prevent surgery. Treatment options are based on your performance status (PS) or your general level of fitness and ability to perform

daily self-care tasks. Your preferences about treatment are always important.

Treatments like chemotherapy, radiation, or chemoradiation can cause an unresectable tumor to become resectable. This means that in some cases surgery might be possible in some unresectable cancers after chemoradiation, radiation therapy, or systemic therapy.

PS 0 or 1

A score of 0 means you are fully active. A score of 1 means you can do all self-care activities but are unable to do hard physical work.

For PS 0 or 1 (fully active), the options are:

- Chemoradiation
- Systemic therapy followed by radiation therapy or chemoradiation. The preferred systemic therapy is docetaxel with cisplatin and 5-FU. Paclitaxel with cisplatin and 5-FU is also an option.
- Radiation therapy

PS 2

A score of 2 means you can do most self-care tasks and spend most of waking time out of bed but are unable to do any work.

For PS 2, the options are:

- Chemoradiation (preferred)
- Radiation therapy

PS 3

A score of 3 means you need help with some self-care tasks and spend most of waking time in bed.

For PS 3, the options are:

- Palliative radiation therapy
- Systemic therapy, **see Guide 5**
- Best supportive care

Guide 5

Systemic therapy options: Recurrent, unresectable, or metastatic disease

Preferred	<p>First-line:</p> <ul style="list-style-type: none"> • Pembrolizumab with platinum-based chemotherapy (cisplatin or carboplatin) and 5-FU • Pembrolizumab (for tumors that express PD-L1 with combined positive score of 1 or more) 	<p>Next-line (if not used before):</p> <ul style="list-style-type: none"> • Nivolumab (if disease progresses on or after platinum-based chemotherapy) • Pembrolizumab (if disease progresses on or after platinum-based chemotherapy)
Other recommended	<p>Combined drugs:</p> <ul style="list-style-type: none"> • Cetuximab with platinum-based chemotherapy and 5-FU • Cisplatin with cetuximab • Platinum-based chemotherapy with docetaxel or paclitaxel • Cisplatin with 5-FU • Platinum-based chemotherapy with docetaxel and cetuximab • Platinum-based chemotherapy with paclitaxel and cetuximab • Pembrolizumab with platinum-based chemotherapy and docetaxel • Pembrolizumab with platinum-based chemotherapy and paclitaxel 	<p>Single drugs:</p> <ul style="list-style-type: none"> • Cisplatin • Carboplatin • Paclitaxel • Docetaxel • 5-FU • Methotrexate • Cetuximab • Capecitabine • Afatinib (next-line only, if disease progresses on or after platinum-based chemotherapy)
Used in some cases	<ul style="list-style-type: none"> • Cetuximab with nivolumab • Cetuximab with pembrolizumab • Paclitaxel with cetuximab • Docetaxel with cetuximab • Pembrolizumab (for MSI-H, dMMR, or TMB-H tumors) • Cisplatin with pemetrexed (for PS 0 or PS 1) • Gemcitabine with paclitaxel • Nivolumab with ipilimumab (for tumors with combined positive score of 20 or more and first-line only) 	

Note: A platinum-based chemotherapy is cisplatin or carboplatin.

Supportive care is health care given to prevent, reduce, and relieve suffering, and to improve quality of life. Best supportive care, supportive care, and palliative care often mean the same thing.

Recurrent or persistent disease

Recurrent disease is cancer that has returned after a disease-free period. Persistent disease is cancer that remains after treatment. It might include cancer that has grown or spread during treatment or is resistant to the treatment.

Recurrent or persistent disease treatment options are based on:

- If you had radiation therapy before, and
- If the tumor can be removed with surgery (resectable) or cannot be removed with surgery (unresectable).

If surgery is an option

A resectable tumor can be removed with surgery. If surgery is done, it might be followed by radiation therapy (RT), chemoradiation, or a clinical trial. A clinical trial is preferred in some cases. Surgery is not the only option for a resectable tumor, particularly if the surgery is anticipated to affect swallowing or speaking. In these cases, other options include targeted therapy, immunotherapy, chemoradiation, or systemic therapy followed by RT or chemoradiation.

If surgery is not an option

An unresectable tumor cannot be removed with surgery. Sometimes, an unresectable tumor can become resectable after other treatments. Treatment options include those found in the "Unresectable" section on page 47.

Metastatic disease

Metastatic disease is cancer that has spread through the bloodstream to distant areas of the body. A clinical trial is preferred for metastatic disease. Depending on your overall health, your ability to perform activities of daily living (ADLs), your preferences about treatment, and the location and number of metastases, treatment options also include systemic therapy, surgery, radiation therapy, or chemoradiation. Palliative surgery and palliative radiation therapy along with other types of supportive care might be given to relieve pain, discomfort, swallowing difficulties, and side effects caused by cancer. For systemic therapy options, **see Guide 5**.

Key points

- ▶ Advanced mouth cancer or very advanced cancer is cancer that remains after treatment (persistent cancer) or cancer that has returned after a cancer-free period (recurrence). It also includes cancer that cannot be removed with surgery (unresectable) or cancer that has spread to near (locoregional) or distant (metastatic) sites through the bloodstream.
- ▶ Treatment is based on the size and location of the tumor(s), if there is cancer in the lymph nodes, and what treatment you had before. Your overall health and preferences about treatment are also important.
- ▶ A resectable tumor can be removed with surgery. An unresectable tumor cannot be removed with surgery because it is too close to vital organs. Sometimes an unresectable tumor can become resectable after treatment with chemoradiation, radiation therapy, or systemic therapy.
- ▶ Metastatic disease is cancer that has spread through the bloodstream to distant areas of the body. A clinical trial is preferred for metastatic disease.

Standard of care is the best-known way to treat a particular disease based on past clinical trials. There may be more than one treatment regimen that is considered standard of care. Ask your care team what treatment options are available and if a clinical trial might be right for you.



7

Making treatment decisions

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- 53 Questions to ask
- 62 Resources

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

It's your choice

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

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 decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments
- Your feelings about pain or side effects
- Cost of treatment, travel to treatment centers, and time away from school or 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 care team. If you take the time to build a relationship with your care team, 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

Possible questions to ask your care team 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 about testing and diagnosis

1. What tests will I have? How often will they be repeated?
2. Will my insurance pay for this test?
3. How soon will I know the results and who will explain them to me?
4. What will you do to make me comfortable during testing?
5. How will my biopsy be performed? What else might be done at this time?
6. Is my cancer resectable or unresectable? What does this mean?
7. Is the cancer early stage, locally advanced, advanced, or metastatic?
8. Is cancer in any other areas like my lymph nodes or lungs?
9. What does the cancer stage mean in terms of length of survival and quality of life?

Questions about your care team's experience

1. What is your experience treating this cancer? What else do you treat?
2. What is the experience of those on your team?
3. How many people like me (of the same age, gender, race) have you treated?
4. Will you be consulting with experts to discuss my care? Whom will you consult?
5. How many procedures like the one you're suggesting have you done?
6. Is this treatment a major part of your practice?
7. How many of your patients have had complications? What were the complications?
8. How many of these surgeries have you done?
9. Who will manage my day-to-day care?

Questions about options

1. What will happen if I do nothing?
2. How do my age, overall health, and other factors affect the options?
3. Which option is proven to work best for my cancer, age, overall health, and other factors?
4. What are the possible complications and side effects? Are any life-threatening?
5. What can be done to prevent or relieve the side effects of treatment?
6. Am I a candidate for a clinical trial? Can I join a clinical trial at any time?
7. What decisions must be made today?
8. Is there a social worker or someone who can help me decide about treatment?
9. Is there a hospital or treatment center you can recommend for treatment?
10. Can I go to one hospital for surgery and a different center for radiation therapy?

Questions about treatment

1. Which treatment(s) do you recommend and why?
2. Does the order of treatment matter?
3. When will I start treatment?
4. How long will treatment likely take?
5. What should I expect from treatment?
6. What will you do to make me comfortable during treatment?
7. How much will my insurance pay for treatment?
8. Are there programs to help me pay for treatment?
9. What are the chances my cancer will return after treatment?
10. I would like a second opinion. Is there someone you can recommend?

Questions about surgery

1. What will be removed during surgery?
2. How will surgery affect my ability to taste, smell, chew, breathe, talk, or swallow?
3. Does my cancer involve any veins, arteries, or nerves and how might this affect surgery?
4. Will I have or need more than one surgery?
5. Will I have reconstruction surgery after surgery to remove the tumor?
6. Will I have a scar and where will it be located?
7. How long will recovery take and what should I expect?
8. How much pain will I be in? What will be done to manage my pain?
9. What treatment will I have before, during, or after surgery?
10. How can I prepare for surgery and what to expect after surgery?

Questions about radiation therapy

1. What type of radiation therapy (RT) will I have?
2. What will you target?
3. What is the goal of this RT?
4. How will RT affect my ability to taste, smell, chew, breathe, talk, or swallow?
5. How many treatment sessions will I require? Can you do a shorter course of RT?
6. Do you offer this type of RT here? If not, should I be referred to someone who does?
7. What side effects can I expect from RT?
8. Should I eat or drink before RT?
9. Will I be given medicine to help me relax during RT?
10. What should I wear?

Questions about side effects

1. What are the side effects of this treatment?
2. How are these side effects treated?
3. How long will these side effects last?
4. What side effects should I watch for that could be life-threatening?
5. When should I call my care team?
6. What should I do on weekends and other non-office hours?
7. What emergency department or ER should I go to?
8. Will my treatment team be able to communicate with the ER team?
9. What medicines can I take to prevent or relieve side effects?
10. What can I do to help with pain and other side effects?

Questions about clinical trials

1. What clinical trials are available for my type and stage 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 treatments 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 about resources and support

1. Who can I talk to about help with housing, food, and other basic needs?
2. What help is available for transportation, childcare, and home care?
3. How much will I have to pay for treatment?
4. What help is available to pay for medicines and other treatment?
5. What other services are available to me and my caregivers?
6. How can I connect with others and build a support system?
7. How can I find in-person or online support?
8. Who can help me with my concerns about missing work or school?
9. Who can I talk to if I don't feel safe at home, at work, or in my neighborhood?
10. How can I get help to stop smoking or vaping?

Resources

Bag It

bagitcancer.org

Cancer Hope Network

Cancerhopenetwork.org

Head and Neck Cancer Alliance

Headandneck.org

HPV Cancers Alliance

hpvca.org

MedlinePlus

medlineplus.gov/cancers

National Coalition for Cancer Survivorship

canceradvocacy.org

National Cancer Institute (NCI)

cancer.gov/types/head-and-neck

Oral Cancer Foundation

Oralcancerfoundation.org

Support for People with Oral and Head and Neck Cancers

Spohnc.org

THANC Foundation

Thancfoundation.org

Triage Cancer

trriagecancer.org



share with us.

Take our survey,
and help make the
NCCN Guidelines for Patients
better for everyone!

NCCN.org/patients/comments



Words to know

alveolar ridge

The bony, raised area of the upper (maxilla) and lower (mandible) jaw that holds the sockets of the teeth.

biopsy

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

buccal mucosa

The inner lining of the cheeks.

cancer stage

A rating of the growth and spread of cancer.

carcinoma

Cancer that starts in cells that form the lining of organs and structures in the body.

chemotherapy

Drugs that kill cancer cells by damaging or disrupting the making of the genetic code.

clinical stage (c)

Rating the extent of a tumor based on tests before treatment.

clinical trial

Research on a test or treatment to assess its safety or how well it works.

computed tomography (CT)

A test that combines many x-rays to make pictures of the inside of the body.

contrast

A substance put into your body to make clearer pictures during imaging tests.

deoxyribonucleic acid (DNA)

A chain of chemicals in cells that contains coded instructions for making and controlling cells.

distant recurrence

Cancer that has come back after treatment and is found in a part of the body far from the first (primary) tumor.

first-line treatment

The first drug or set of drugs given to treat cancer.

gene

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

gingiva

The gums. The tissue of the upper and lower jaws that surrounds the base of the teeth.

hard palate

Bony part of the roof of the mouth.

histology

The structure of cells, tissue, and organs as viewed under a microscope.

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.

local recurrence

Cancer that has come back after treatment in or near the same place as the first (primary) tumor.

lymph

A clear fluid containing white blood cells.

lymph node

A small group of disease-fighting cells located throughout the body.

lymph vessels

Tubes that carry lymph—a clear fluid containing white blood cells that fight disease and infection—throughout the body and connect lymph nodes to one another.

magnetic resonance imaging (MRI)

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

medical oncologist

A doctor who's an expert in cancer drugs.

metastasis

The spread of cancer cells from the first tumor to another body part.

mutation

An abnormal change.

nasal cavity

The space inside the nose. The nasal cavity lies above the bone that forms the roof of the mouth and curves down at the back to join the throat. It is divided into 2 sections called nasal passages. Air moves through these passages during breathing. The nasal passages filter and warm the air, and make it moist before it goes into the lungs. They also contain special cells that are involved in the sense of smell.

nasopharynx

The part of the throat that is behind the nose.

oral cavity

Refers to the mouth. It includes the lips, the lining inside the cheeks and lips, the front two thirds of the tongue, the upper and lower gums, the floor of the mouth under the tongue, the bony roof of the mouth, and the small area behind the wisdom teeth.

oropharynx

The middle part of the throat.

palliative care

Treatment for symptoms of a disease. Also sometimes called supportive care.

palliative radiation

Radiation therapy used to relieve symptoms caused by the cancer.

Panorex x-ray

A picture of the inside of the entire mouth, including jaw.

paranasal sinus

One of many small hollow spaces in the bones around the nose. Paranasal sinuses are named after the bones that contain them: frontal (the lower forehead), maxillary (cheekbones), ethmoid (beside the upper nose), and sphenoid (behind the nose). The paranasal sinuses open into the nasal cavity (space inside the nose) and are lined with cells that make mucus to keep the nose from drying out during breathing.

pathologic stage (p)

A rating of the extent of cancer based on microscopic review after treatment.

pathologist

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

positron emission tomography (PET)

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

primary treatment

The main treatment used to rid the body of cancer.

primary tumor

The first mass of cancer cells in the body.

prognosis

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

radiation oncologist

A doctor who's an expert in radiation treatment.

radiation therapy (RT)

A treatment that uses high-energy rays.

radiologist

A doctor who is an expert in imaging tests.

radiotracer

A substance that releases small amounts of energy (radiation) that is put into the body to make pictures clearer.

recurrence

The return of cancer after a cancer-free period. Also called relapse.

resectable

Cancer that can be removed with surgery.

retromolar trigone

The area behind the wisdom teeth

resection

Surgery to remove a tumor.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

soft palate

Muscular, soft portion of the back of the roof of the mouth. Behind the hard palate. Part of the oropharynx.

staging

The process of rating and describing the extent of cancer in the body.

standard of care

The best-known way to treat a particular disease based on past clinical trials. There

may be more than one treatment regimen that is considered standard of care.

supportive care

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

targeted therapy

Treatment with drugs that target a specific or unique feature of cancer cells.

throat

A hollow, muscular tube inside the neck that starts behind the nose and ends at the top of the trachea (windpipe) and esophagus (the tube that goes to the stomach).

treatment plan

A written course of action through cancer treatment and beyond.

tumor

An abnormal mass of cells.

ultrasound (US)

A test that uses sound waves to take pictures of the insides of the body.

unresectable

Cancer that can't be completely removed by surgery.

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This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Head and Neck Cancers Version 1.2024. It was adapted, reviewed, and published with help from the following people:

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Philadelphia, Pennsylvania
800.789.7366 • penncancer.org

**Case Comprehensive Cancer Center/
University Hospitals Seidman Cancer Center and
Cleveland Clinic Taussig Cancer Institute**
Cleveland, Ohio
UH Seidman Cancer Center
800.641.2422 • uhhospitals.org/services/cancer-services
CC Taussig Cancer Institute
866.223.8100 • my.clevelandclinic.org/departments/cancer
Case CCC
216.844.8797 • case.edu/cancer

City of Hope National Medical Center
Duarte, California
800.826.4673 • cityofhope.org

**Dana-Farber/Brigham and Women's Cancer Center |
Mass General Cancer Center**
Boston, Massachusetts
617.732.5500 • youhaveus.org
617.726.5130 • massgeneral.org/cancer-center

Duke Cancer Institute
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888.275.3853 • dukecancerinstitute.org

Fox Chase Cancer Center
Philadelphia, Pennsylvania
888.369.2427 • foxchase.org

Fred & Pamela Buffett Cancer Center
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402.559.5600 • unmc.edu/cancercenter

Fred Hutchinson Cancer Center
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206.667.5000 • fredhutch.org

Huntsman Cancer Institute at the University of Utah
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Jacksonville, Florida
Rochester, Minnesota
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904.953.0853 • Florida
507.538.3270 • Minnesota
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800.525.2225 • mskcc.org

Moffitt Cancer Center
Tampa, Florida
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Roswell Park Comprehensive Cancer Center
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877.275.7724 • roswellpark.org

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**St. Jude Children's Research Hospital/
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San Francisco, California
800.689.8273 • cancer.ucsf.edu

University of Colorado Cancer Center

Aurora, Colorado
720.848.0300 • coloradocancercenter.org

University of Michigan Rogel Cancer Center

Ann Arbor, Michigan
800.865.1125 • rogelcancercenter.org

University of Wisconsin Carbone Cancer Center

Madison, Wisconsin
608.265.1700 • uwhealth.org/cancer

UT Southwestern Simmons Comprehensive Cancer Center

Dallas, Texas
214.648.3111 • utsouthwestern.edu/simmons

Vanderbilt-Ingram Cancer Center

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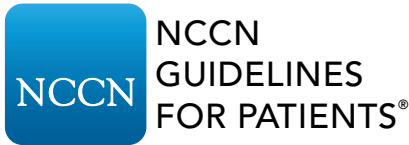
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Mouth Cancer

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