If You Have Oral or Oropharyngeal Cancer

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What is oral cavity and oropharyngeal cancer?

Oral cavity and oropharyngeal cancers are cancers that start in the head and neck area. Cancer that starts in the mouth is called oral cavity cancer. Cancer that starts in the middle part of the throat is called oropharyngeal cancer. These cancers start when cells in the oral cavity or oropharynx grow out of control and crowd out normal cells.

Cancer that starts in the head and neck area can have many different names depending on where the cancer starts. Ask your doctor to write down the exact kind of cancer you have because it can be confusing.

The information after the picture below is about oral cavity and oropharyngeal cancers. If you are not sure where the cancer is, ask your doctor to use these pictures to show you.
**The mouth and throat**

Cancer cells can spread to other parts of the body. Cancer cells in the oral cavity or
oropharynx can sometimes travel to the lungs and grow there. When cancer cells do this, it’s called metastasis. To doctors, the cancer cells in the new place look just like the ones from the oral cavity or oropharynx where it started.

Cancer is always named for the place where it starts. So when oral cavity or oropharyngeal cancer spreads to the lung (or any other place), it’s still called oral cavity or oropharyngeal cancer. It’s not called lung cancer unless it starts from cells in the lung.

**Are there different types of oral cavity and oropharyngeal cancer?**

The most common type of cancer in the oral cavity and oropharynx is called *squamous cell carcinoma (cancer)*. These cancers start in the squamous cells that line the mouth (oral cavity) and the middle part of the throat (oropharynx).

**Questions to ask the doctor**

- Why do you think I have cancer?
- Is there a chance I don’t have cancer?
- Would you please write down the kind of cancer you think I might have?
- What will happen next?

**How does the doctor know I have oral cavity and oropharyngeal cancer?**

These cancers may not be found until they cause problems that make the person go to the doctor. Sometimes changes are seen during a routine visit to the doctor or dentist.

The doctor will ask you questions about your health and your lifestyle habits (like if you smoke or drink alcohol), will examine you, and order tests to find out what is causing your symptoms. If signs are pointing to oral cavity or oropharyngeal cancer, you may be sent to see a doctor who focuses on diseases of the ear, nose, and throat (called an ENT doctor, an otolaryngologist, or a head and neck surgeon).

Here are some of the tests you might need:

**Complete head and neck exam**: The doctor will check the head and neck area, looking and feeling for any abnormal areas, including the mouth and middle part of the throat. The lymph nodes in the neck will be felt for any signs of cancer. Because some
parts of the mouth and throat are not easily seen, the doctor may use mirrors, lights, and/or special fiber-optic scopes including the mouth and middle part of the throat to look at these areas.

**Panendoscopy:** This exam is done in the operating room after you are given drugs to make you sleep. The surgeon looks inside your nose, mouth, and throat and sometimes the esophagus (swallowing tube) and trachea (windpipe) through thin tubes called scopes and may take out pieces of tissue (biopsies) to be checked in the lab.

**Biopsy:** For this test, the doctor takes out a small piece of tissue with surgery, a needle, or scraping the abnormal area, where the cancer seems to be. The tissue is checked for cancer cells. This is the best way to know for sure if you have cancer.

**Gene and protein tests:** The cancer cells in the biopsy tissue might be tested for genes or proteins. Knowing which genes or proteins your cancer has can help the doctor decide if treatments like immunotherapy might help.

The cancer might also be tested for a protein that is linked to HPV infection\(^3\). If HPV infection is found (meaning the tumor has that protein), this might have an effect on the cancer stage\(^4\) and treatment options.

**CT scan:** This is also called a CAT scan. It’s a special kind of x-ray that takes detailed pictures to see if the cancer has spread to the lymph nodes, lungs, or other organs. CT scans can also be used to help do a biopsy (see above).

**MRI scan:** MRI scans use radio waves and strong magnets instead of x-rays to take detailed pictures. MRIs can be used to learn more about the size of the cancer and if it has spread to nearby structures or other areas of the body.

**Chest x-rays:** X-rays may be done to see if the cancer has spread to the lungs.

**PET scan:** A PET scan uses a special kind of sugar that can be seen inside your body with a special camera. If there is cancer, this sugar shows up as “hot spots” where the cancer is found. This test can help show if the cancer might have spread.

**Barium swallow:** For this test, x-rays are taken while you swallow a liquid with barium in it. Barium coats the inside surface of the mouth and throat and helps get a good picture. This test might be done if you are having trouble swallowing because it shows how your throat looks as you swallow.

**Ultrasound:** For this test, a small wand is moved around on your skin. It gives off sound waves and picks up the echoes as they bounce off tissues. The echoes are made into a
picture on a computer screen. It’s sometimes used to help find cancer in the lymph nodes in the neck to see if it has spread.

Dental exam: Your dentist will probably do a complete exam and maybe some x-rays of your teeth and jaw before any radiation is given because radiation can damage the saliva (spit) glands and cause dry mouth. The dentist might also remove bad teeth to lower the chances of cavities and infection.

Hearing test: The most common chemo drug used to treat oral cavity and oropharyngeal cancer, cisplatin, can cause ringing in the ears or even hearing loss. You might have your hearing checked (with an audiogram) before starting treatment and your chemotherapy might be changed if your hearing is poor to start with.

Nutrition and speech tests: A nutritionist might check your nutrition status before, during, and after treatment to try and keep your body weight and protein levels as normal as possible. A speech therapist might test how well you swallow and speak. They might give you exercises to do to help strengthen the muscles so that you can eat and talk normally after finishing treatment.

Blood tests: Blood tests are not used to find cancer of the oral cavity or oropharynx, but they can tell the doctor more about your overall health, like your kidney or liver function.

Quit smoking: If you smoke cigarettes or use chewing tobacco, your doctor might talk to you about quitting all tobacco products before starting treatment. Smoking while getting cancer treatment can cause problems such as poor wound healing after surgery, more side effects from chemo, and a higher chance of infection.

Questions to ask the doctor

- What tests will I need to have?
- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

How serious is my cancer?
If you have oral cavity or oropharyngeal cancer, the doctor will want to find out how far it has spread\(^5\). This is called staging. Knowing the stage will help your doctor decide what type of treatment is best for you.

The stage describes the spread of the cancer in the place it started. It also tells if the cancer has spread to nearby organs or to organs farther away.

Your cancer can be stage 0, 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number, like stage 4, means a more serious cancer that has spread from where it started. Be sure to ask the doctor about the cancer stage and what it means for you.

Questions to ask the doctor

- Do you know the stage of the cancer?
- If not, how and when will you find out the stage of the cancer?
- Would you explain to me what the stage means in my case?
- Based on the stage of the cancer, how long do you think I’ll live?
- What will happen next?

What kind of treatment will I need?

There are many ways to treat cancer of the oral cavity or oropharynx.

- Surgery and radiation are used to treat only the cancer. They do not affect the rest of the body.
- Chemotherapy, targeted therapy drugs, and immunotherapy drugs go through the whole body. They can reach cancer cells almost anywhere in the body.

You might get more than one type of treatment. The treatment plan that’s best for you will depend on:

- Where the cancer started growing – the oral cavity (mouth) or the oropharynx (the middle part of the throat right behind the mouth)
- The stage of the cancer
- If the cancer is linked to an HPV infection
- The chance that a type of treatment will cure the cancer or help in some way
- How treatment will affect the way you talk, breathe, and eat
• Your age
• Other health problems you have
• Your feelings about the treatment and the side effects that come with it

Surgery for oral cavity or oropharyngeal cancer

Some of these cancers are in places that are hard to operate on. Still, surgery may be used to take out the cancer and an edge of healthy tissue around it. In some cases, all or part of the tongue, throat, voice box, or jaw bone may need to be removed. Surgery may also be used to take out lymph nodes in the neck that might have cancer.

Surgery can also be used to help you do things that the cancer may have changed. For instance, if you can’t swallow because of the tumor, surgery may be done to put in a feeding tube. Some surgeries can even help rebuild part of the throat.

Side effects of surgery

Any type of surgery can have risks and side effects. Ask the doctor what you can expect. If you have problems, let your doctors know. Doctors who treat people with oral cavity and oropharyngeal cancers should be able to help you with any problems that come up.

Radiation treatments

Radiation uses high-energy rays (like x-rays) to kill cancer cells. It can be given alone or along with chemotherapy (called chemoradiation). Radiation can also be used to help with symptoms such as pain, bleeding, trouble swallowing, or other problems that happen if the cancer has grown very large or has spread to other areas.

There are 2 main ways radiation can be given.

• External beam radiation aims high-energy rays at the cancer from a machine outside the body. This is the most common type of radiation used to treat these cancers.
• Brachytherapy is another kind of radiation. To do this, the doctor uses an endoscope (a long, flexible tube) to put small radioactive seeds very close to the cancer.
**Side effects of radiation treatments**

If your doctor suggests radiation treatment, talk about what side effects might happen. Side effects depend on the type of radiation that’s used and the part of your body that’s treated. The most common side effects are:

- Skin changes where the radiation is given
- Feeling very tired (fatigue)
- Hoarse voice
- Taste changes
- Mouth and throat sores
- Dry mouth
- Trouble swallowing or eating

Most side effects get better after treatment ends and many can be treated. Some might last longer. Ask your cancer care team what you can expect.

**Chemo**

Chemo is the short word for chemotherapy – the use of drugs to fight cancer. The drugs may be given into a vein or taken as pills. These drugs go into the blood and spread through the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. This gives the body time to recover. Most of the time, 2 or more chemo drugs are given. Treatment often lasts for many months.

For oral cavity and oropharyngeal cancer, chemo is often given along with radiation. This is called **chemoradiation**.

**Side effects of chemo**

Chemo can make you feel very tired, sick to your stomach, and cause your hair to fall out. But most of these problems go away after treatment ends. Other side effects like hearing problems or nerve damage can last a long time.

There are ways to treat most chemo side effects. If you have side effects, tell your cancer care team so they can help.

**Targeted drug therapy**

Targeted therapy drugs may be used to treat oral cavity or oropharyngeal cancer.
These drugs affect mainly cancer cells and not normal cells in the body. They may work even if other treatment doesn’t. These drugs have different side effects from chemo.

**Side effects of targeted drug therapy**

Side effects of targeted drug therapy depend on which drug is used. These drugs can make you feel sick to your stomach and cause low blood counts. They can also cause skin changes of the hands and feet. These side effects usually go away after treatment ends.

There are ways to treat most of the side effects caused by targeted therapy drugs. If you have side effects, talk to your cancer care team so they can help.

**Immunotherapy**

Immunotherapy is treatment that either boosts your own immune system or uses man-made versions of parts of the immune system that attack the oral cavity or oropharyngeal cancer cells. Immunotherapy drugs may be given into a vein.

**Side effects of immunotherapy**

Immunotherapy can cause many different side effects depending on which drug is used. These drugs may make you feel tired, sick to your stomach, or cause a rash. Most of these problems go away after treatment ends.

There are ways to treat most of the side effects caused by immunotherapy. If you have side effects, talk to your cancer care team so they can help.

**Clinical trials**

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find one that’s studying the kind of cancer you have, it’s up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

If you would like to be in a clinical trial, start by asking your doctor if your clinic or hospital conducts clinical trials. See Clinical Trials to learn more.
What about other treatments I hear about?

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be vitamins, herbs, special diets, and other things. You may be curious about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you’re thinking about using, whether it’s a vitamin, a diet, or anything else.

Questions to ask the doctor

- What treatment do you think is best for me?
- What’s the goal of this treatment? Do you think it could cure the cancer?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- Will I be able to talk normally after surgery?
- Will the treatment affect the way I look? Can anything be done to fix that?
- Has my cancer been tested for HPV infection?
- Will I need a feeding tube?
- Will I need other types of treatment, too?
- What’s the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What’s the next step?

What will happen after treatment?

You’ll be glad when treatment is over. For years after treatment ends, you will still have appointments with your cancer doctor. Be sure to go to all of these follow-up visits. You will have exams, blood tests, and maybe other tests to see if the cancer has come back.
Follow-up doctor visits after treatment may be needed as often as every few months for the first year, every 3 to 6 months during the 2nd year, and a little less often after that. During these visits, your doctor will ask about any symptoms you’re having, if you are smoking cigarettes or using chewing tobacco, and will do a physical exam. Endoscopy exams, blood tests, dental exams, or imaging tests (like MRI or CT scans) may be done to look for signs of cancer or treatment side effects. Your doctor will tell you which tests should be done and how often based on the stage of your cancer and the type of treatment you had.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your doctor to find out what you can do to feel better or to help you quit smoking. You can’t change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as well as you can.

For connecting and sharing during a cancer journey

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the Cancer Survivors Network (CSN), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

Hyperlinks

10. csn.cancer.org/
11. www.caringbridge.org/
12. www.cancer.org
13. www.cancer.org

Words to know

**Biopsy** (BY-op-see): taking out a small piece of tissue to see if there are cancer cells in it

**Epiglottis** (EP-uh-GLOT-is): A thin, valve-like, cartilage flap at the base of the tongue that covers the vocal cord area when you swallow. This keeps food and drink from getting into the windpipe.

**Esophagus** (eh-SOF-uh-gus): the tube that carries food from the mouth to the stomach

**Glottis** (GLOT-is): the part of the larynx that contains the vocal cords

**Hypopharynx** (hi-po-FAIR-ingks): the lower part of the throat, from the voice box down to the esophagus

**Larynx** (lair-ingks): the voice box, which sits below the base of the tongue and at the top of the windpipe. It contains the vocal cords, which make sound.

**Metastasis** (muh-TAS-tuh-sis): cancer cells that have spread from where they started to other places in the body

**Nasal cavity**: the inside of the nose above the roof of the mouth

**Nasopharynx** (NAY-zoh-FAIR-ingks): the part of the throat that’s behind the nose

**Oropharynx** (OR-oh-FAIR-ingks): the part of the throat that’s behind the mouth

**Subglottis** (sub-GLOT-is): the lower part of the larynx, from just under the voice box to the top of the windpipe

**Supraglottis** (sub-GLOT-is): the upper part of the larynx, above the voice box
Trachea (TRAY-key-uh): the windpipe, the big tube that carries air in and out of the lungs

Voice box: the larynx, which sits below the base of the tongue and at the top of the windpipe. It contains the vocal cords which make sound.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (www.cancer.org)12. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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