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#### **EASY READING**

# If You Have Salivary Gland Cancer

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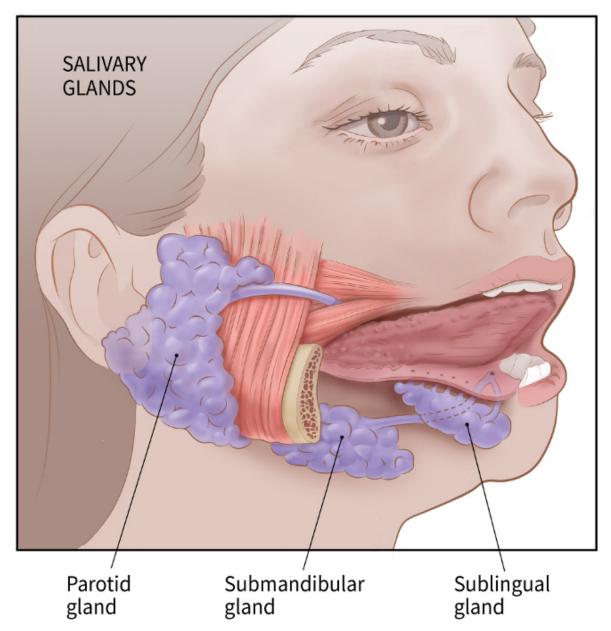
# What is salivary gland cancer?

Salivary gland cancer can start in any of the salivary glands. It can have many names depending on which type of cell the cancer starts in. All of these cancers start when cells in part of a salivary gland grow out of control and crowd out normal cells. Ask your doctor to write down the exact kind of cancer you have because it can be confusing.

Cancer cells can spread to other parts of the body. Cancer cells in a salivary gland can sometimes travel to the lung 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 salivary gland where it started.

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

Ask your doctor to use this picture to show you where the cancer is.



# Different kinds of salivary gland cancer

There are many types of salivary gland cancers<sup>1</sup>. Your doctor can tell you more about the type you have. Most salivary gland cancers start in the parotid gland.

# 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 salivary gland 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. 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).

The doctor will ask you questions about your health, your smoking and alcohol history, any exposures to workplace chemicals, and will physically exam you. If you have signs pointing to salivary gland cancer, more tests will be done. Here are some of the <u>tests</u> you may need<sup>2</sup>:

**Complete head and neck exam:** The doctor will check your face, mouth, and neck, looking and feeling for any abnormal areas. The lymph nodes in the neck will be felt for swelling, which could be a sign of cancer. Because some parts of the mouth and throat are not easy to see, the doctor may use mirrors, lights, and/or special fiber-optic scopes to look at these areas.

**Biopsy:** For this test, the doctor takes out a small piece of tissue where the cancer seems to be and checks it 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 also be tested for certain genes or proteins. Knowing which genes or proteins your cancer has can help the doctor decide if treatments like immunotherapy or targeted drug therapy might help.

**CT scan:** This is also called a CAT scan. It's a special kind of x-ray that takes detailed pictures to show exactly where the cancer is growing. It can also help show if the cancer has spread to the lymph nodes, other organs, or other parts of your head or neck. CT scans can also be used to help do a biopsy.

**MRI scan:** MRIs 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.

**X-rays:** X-rays might be done to check for tumors or weakened bone in your jaw or

teeth before getting radiation treatment. Your chest might also get x-rayed to see if the cancer has spread to the lungs.

**PET scan:** A PET scan uses a special type 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.

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

**Nutrition and speech tests:** A nutritionistmight 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. After you finish treatment, they might give you exercises to help strengthen the muscles that help you eat and talk normally.

**Hearing test:** The chemo drug 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.

**Dental exam:** Your dentist will probably examine and x-ray your teeth and remove any bad teeth before any radiation is given because radiation can damage the saliva (spit) glands and cause dry mouth. Bad teeth and dry mouth can increase the chances of cavities and 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 salivary gland cancer, the doctor will want to find out <u>how far it has spread</u><sup>3</sup>. This is called staging. You might have heard other people say that their cancer was

stage 1 or stage 2.

The stage describes the spread of the cancer from the place it started. It also tells if the cancer has spread to other parts of your body that are close by or farther away. Knowing the stage will help your doctor decide what type of treatment is best for you.

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.

The cancer cells in the biopsy sample will also be graded. This helps doctors predict how fast the cancer is likely to grow and spread. Cancer cells are graded based on how much they look like normal cells. Grades 1, 2, and 3 are used. Cells that look very different from normal cells are given a higher grade (3) and tend to grow faster. Ask the doctor to explain the grade of your cancer. The grade helps the doctor decide which treatment is best for you.

#### Questions to ask the doctor

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

## What kind of treatment will I need?

Smoking during cancer treatment is linked to more side effects, worse outcomes, and reduced benefit of treatment. It is best to stop smoking completely before starting treatment. Smoking also increases the risk of the cancer coming back after treatment as well as the risk of getting a new cancer. Quitting smoking for good is the best way to improve your chance of survival.

There are many ways to treat salivary gland cancer<sup>4</sup>:

- Surgery and radiation are used to treat only the cancer. They do not affect the rest of the body.
- Chemo drugs, targeted drug therapy, immunotherapy go through the whole body.

They can reach cancer cells almost anywhere in the body.

You might get more than one type of treatment. For example, chemotherapy or targeted drug therapy might be given at the same time as radiation.

The treatment plan that's best for you will depend on:

- Where the cancer started growing
- The specific type of salivary gland cancer
- The stage and grade of the cancer
- 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<sup>5</sup> that might come with it

# Surgery for salivary cancer

Some of these cancers might be in places that are hard to operate on. Still, <u>surgery</u><sup>6</sup> is the most common way to take out all the cancer and an edge of healthy tissue around it. Surgery may also be used to take out lymph nodes in the neck that might have cancer cells.

## 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 salivary gland cancers should be able to help you with any problems that come up.

#### **Radiation treatments**

Radiation<sup>7</sup> uses high-energy rays (like x-rays) to kill cancer cells. Radiation is aimed at the cancer from a machine outside the body. This is called external beam radiation.

Radiation might be used to treat salivary gland cancers:

 As the main treatment for tumors that can't be taken out because of how big they are or where they are

- To kill any cancer cells that may be left after surgery
- To ease problems caused by the cancer such as pain, bleeding, or trouble swallowing

## Side effects of radiation treatments

If your doctor suggests radiation treatment, ask what side effects you might have. 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 of radiation 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
- Bone damage
- Thyroid gland damage
- Nerve damage

Your doctor may have you see a dentist before starting radiation. This is done to fix any problems with your teeth or gums that might get worse with radiation.

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

#### Chemo

<u>Chemo</u><sup>8</sup>, the short word for chemotherapy,is 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 most of the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Most of the time, 2 or more chemo drugs are given. Treatment often lasts for many months.

Chemo is not usually a treatment for salivary gland cancer, but sometimes it's given along with radiation. It may help the radiation work better. Other times, it might be used if surgery or radiation did not work.

#### Side effects of chemo

Chemo can make you feel very tired, sick to your stomach, and your hair might 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

<u>Targeted drugs</u><sup>9</sup> may be used to treat salivary gland cancer. These drugs affect mainly cancer cells and not normal cells in the body. They may work even if other treatments don'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. There are ways to treat most of the side effects caused by targeted therapy and they usually go away after treatment ends.

If you have side effects, talk to your cancer care team so they can help.

# **Immunotherapy**

<u>Immunotherapy</u><sup>10</sup> is treatment that either boosts your own immune system or uses manmade versions of parts of the immune system that attack the 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 can cause you to feel tired, have a cough, feel sick to your stomach, have a skin rash, poor appetite, constipation, and diarrhea. Most of these problems go away after treatment ends.

More serious side effects might happen if the immune system starts attacking normal parts of the body, which can cause problems in many organs. You may need to stop the immunotherapy drug and take steroids to treat this side effect.

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.

If you would like to learn more about clinical trials, start by asking your doctor if your clinic or hospital takes conducts clinical trials. See Clinical Trials<sup>11</sup> to learn more.

Clinical trials help doctors 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.

#### What about other treatments that I hear about?

When you have cancer you might hear about <u>other ways to treat the cancer or treat your symptoms</u><sup>12</sup>. These may not always be standard medical treatments. These treatments may be vitamins, herbs, special diets, and other things. You may wonder 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?
- What will I look like after surgery?
- Will I be able to talk normally after surgery?
- Will I need other types of treatment, too?
- What is 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 <u>when treatment is over</u><sup>13</sup>. For years after treatment ends, you will see 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 using any products like cigarettes or chewing tobacco, and will do a physical exam. Scope exams, lab tests, 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 think about ways 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 get help to 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 <u>Cancer Survivors Network (CSN)</u><sup>14</sup>, a safe place to connect with others who share similar interests and experiences. We also partner with <u>CaringBridge</u><sup>15</sup>, 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**

- 1. <a href="https://www.cancer.org/cancer/salivary-gland-cancer/about/what-is-salivary-gland-cancer.html">www.cancer.org/cancer/salivary-gland-cancer/about/what-is-salivary-gland-cancer.html</a>
- 2. <u>www.cancer.org/cancer/salivary-gland-cancer/detection-diagnosis-staging/how-diagnosed.html</u>
- 3. <u>www.cancer.org/cancer/salivary-gland-cancer/detection-diagnosis-staging/staging.html</u>
- 4. www.cancer.org/cancer/salivary-gland-cancer/treating.html
- 5. <u>www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html</u>
- 6. www.cancer.org/cancer/salivary-gland-cancer/treating/surgery.html
- 7. www.cancer.org/cancer/salivary-gland-cancer/treating/radiation-therapy.html
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- 12. <u>www.cancer.org/treatment/treatments-and-side-effects/treatment-types/complementary-and-integrative-medicine.html</u>
- 13. www.cancer.org/cancer/salivary-gland-cancer/after-treatment.html
- 14. csn.cancer.org/
- 15. <a href="www.caringbridge.org/">www.caringbridge.org/</a>
- 16. 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

**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

Parotid glands: the 2 biggest salivary glands that are just in front of and below the ears

Skull: the set of bones that form the head, face, and jaw

**Sublingual glands**: salivary glands that are in the bottom of the mouth under the tongue

Submandibular glands: salivary glands that are under the jaw bone

## 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)<sup>16</sup>. 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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Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

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