Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor or about the chances of the cancer coming back.

- Living as an Oral Cavity and Oropharyngeal Cancer Survivor

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For many people, treatment will successfully remove or destroy oral cavity or oropharyngeal cancer. The end of treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it’s hard not to worry about cancer coming back. This is very common if you’ve had cancer.

For others, the cancer might never go away completely. Some people may get regular treatment with chemotherapy or targeted therapy or other treatments to try and help keep the cancer under control. Learning to live with cancer that does not go away can be difficult and very stressful.

Ask your doctor for a survivorship care plan
Talk with your doctor about developing a survivorship care plan\(^2\) for you. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests you might need in the future, such as early detection (screening) tests\(^3\) for other types of cancer
- A list of possible late- or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- Suggestions for things you can do that might improve your health, including possibly lowering your chances of the cancer coming back, such as diet and physical activity suggestions
- Reminders to keep your appointments with your primary care provider (PCP), who will monitor your general health care

Follow-up care

People with cancer of the oral cavity or oropharynx are at risk of the cancer coming back and are at risk for developing new cancers in the head and neck area\(^4\), so they must be watched closely after treatment. Your cancer care team will discuss which tests should be done and how often based on the type and stage\(^5\) of the cancer, the type of treatment you had, and the chance of the cancer coming back.

After you have completed treatment, you will likely have follow-up visits with your doctor for many years. It's very important to go to all of your follow-up appointments. During these visits, your doctors will ask if you are having any problems and may examine you, and order endoscopies, lab tests, or imaging tests to look for signs of cancer returning, a new cancer, or treatment side effects.

Almost any cancer treatment can have side effects. Some may last for a few weeks to several months, but others can last the rest of your life. Some side effects might not even show up until years after you have finished treatment. Your doctor visits are a good time to ask questions and talk about any changes or problems you notice or concerns you have.

It's important to report any new symptoms to your doctor right away. This might help your doctor find recurrent cancer or a new cancer as early as possible, when the cancer is small and easier to treat.

Doctor visits and tests
If there are no signs of cancer, many doctors will recommend you have a physical exam and some of the tests listed below every few months for the first couple of years after treatment, then every 4 to 6 months or so for the next few years. People who were treated for early-stage cancers may do this less often.

**Endoscopy:** You will be examined with a scope about:

- Every 1 to 3 months during the first year
- Every 2 to 6 months during the second year
- Every 4 to 8 months during the 3rd to 5th years
- Every year after the 5th year

**Quitting smoking:** If you had trouble quitting smoking before treatment, your doctor may recommend counseling as well as medication to help you. **It is very important to quit smoking because even people with early-stage oral cavity or oropharyngeal cancer are at risk of a new smoking-related cancer if they continue to smoke.** See [Stay Away from Tobacco](#) or call 1-800-227-2345 for more information about quitting smoking.

**Blood tests:** If you were treated with radiation to the neck, it might have affected your thyroid gland. You will most likely need regular blood tests to check your thyroid function.

**Imaging:** Chest x-rays and other imaging tests might be used to watch for recurrence or a new tumor, especially if you have new symptoms.

**Dental exams:** People treated with radiation may also have problems with dry mouth and tooth decay, so regular dental exams are often recommended.

**Problems with eating and nutrition:** Cancers of the mouth and throat and their treatments can sometimes cause problems such as loss or change in taste, dry mouth, or even loss of teeth. This can make it hard to eat, which can lead to weight loss and weakness due to poor nutrition.

Some people might need to adjust what they eat during and after treatment or might need nutritional supplements to help make sure they get the nutrition they need. Some may even need a feeding tube placed into the stomach, at least for a short time during and after treatment.

A team of doctors and nutritionists can work with you to help manage your individual nutritional needs. This can help you maintain your weight and get the nutrients you
need. They can also talk to you about swallowing exercises that can help keep these muscles working and give you a better chance of eating normally after treatment. If a dry mouth is making it hard to eat, your doctor may recommend a saliva substitute.

**Speech, hearing, and swallowing rehabilitation:** Radiation, surgery, and certain chemo drugs can lead to problems with speech, swallowing, and hearing. Speech therapists are knowledgeable about speech and swallowing problems and can help you learn to manage them. You might also need to see an audiologist (a specialist in hearing) for devices to improve your hearing, if the treatment affected it.

**Keeping health insurance and copies of your medical records**

Even after treatment, it’s very important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

At some point after your cancer treatment, you might find yourself seeing a new doctor who doesn’t know about your medical history. It’s important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment.

**Can I lower my risk of oral cavity or oropharyngeal cancer progressing or coming back?**

If you have (or have had) oral cavity or oropharyngeal cancer, you probably want to know if there are things you can do that might lower your risk of the cancer growing or coming back, such as exercising, eating a certain type of diet, or taking nutritional supplements. Unfortunately, it’s not yet clear if there are things you can do that will help.

**Quit smoking:** Smoking during cancer treatment is known to reduce the benefit of treatment which can raise your risk of the cancer coming back (recurrence). Smoking also increases the risk of getting a new smoking-related cancer (see Second Cancers below). Survivors of oral cavity and oropharyngeal cancers who continue to smoke are also more likely to die from their cancer. **Quitting smoking for good is the best way to improve your survival. It is never too late to quit.**

Adopting healthy behaviors such as eating well, getting regular physical activity, and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of oral cavity or oropharyngeal cancer or other cancers.

**About dietary supplements**
So far, no dietary supplements\textsuperscript{14} (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of oral cavity or oropharyngeal cancer progressing or coming back. This doesn’t mean that no supplements will help, but it’s important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States. They do not have to be proven effective (or even safe) before being sold, although there are limits on what they’re allowed to claim they can do. If you’re thinking about taking any nutritional supplement, talk to your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

\textbf{If the cancer comes back}

If the cancer does come back (recur), your treatment options will depend on where it is located, what treatments you’ve had before, and your overall health. For more information on how recurrent cancer is treated, see Treatment Options for Oral Cavity and Oropharyngeal Cancer, by Stage\textsuperscript{15}.

For more general information, you may also want to see Understanding Recurrence\textsuperscript{16}.

\textbf{Getting emotional support}

Some amount of feeling depressed, anxious, or worried is normal when cancer is a part of your life. Some people are affected more than others. But everyone can benefit from help and support from other people, whether friends and family, religious groups, support groups, professional counselors, or others. Learn more in Life After Cancer\textsuperscript{17}.

\textbf{Second cancers after oral cavity or oropharyngeal cancer treatment}

People who’ve had oral cavity or oropharyngeal cancer can still get other cancers. In fact, oral cavity or oropharyngeal cancer survivors are at higher risk for getting some other types of cancer.

Cancer survivors can be affected by a number of health problems, but often a major concern is facing cancer again. Cancer that comes back after treatment it is called a recurrence\textsuperscript{18}. But some cancer survivors develop a new, unrelated cancer later. This is called a second cancer.

Being treated for oral cavity or oropharyngeal cancer doesn’t mean you can’t get another cancer.
Survivors of cancers of the oropharynx can get any type of second cancer, but they have an increased risk of:

- Lung cancer\(^{19}\)
- Esophagus cancer\(^{20}\)
- Cancers of the larynx and hypopharynx\(^{21}\)
- Cancer of the oral cavity (including tongue and mouth)
- Another cancer of the oropharynx (this is different than the first cancer coming back)
- Pancreas cancer\(^{22}\)
- Cancer of the bile ducts\(^{23}\)
- Anal cancer\(^{24}\)
- Cancer of the cervix\(^{25}\)
- Colon cancer\(^{26}\)
- Rectal cancer\(^{27}\)
- Stomach cancer\(^{28}\)
- Chronic myeloid leukemia (CML)\(^{29}\)
- Hodgkin lymphoma\(^{30}\)
- Thyroid cancer\(^{31}\)

Many of these cancers are linked to smoking and alcohol use\(^{32}\), which are also risk factors for HPV-negative oropharyngeal cancer.

Survivors of cancer of the oral cavity can get any second cancer, but they have an increased risk of:

- Lung cancer\(^{33}\)
- Esophagus cancer\(^{34}\)
- Cancers of the larynx and hypopharynx\(^{35}\)
- Another cancer of the oral cavity (this is different than the first cancer coming back)
- Cancer of the oropharynx
- Stomach cancer\(^{36}\)
- Liver cancer\(^{37}\)
- Colon cancer\(^{38}\)
- Rectal cancer\(^{39}\)
- Cancer of the cervix\(^{40}\)

Many of these cancers are also linked to smoking and alcohol use, which are also risk
factors for oral cavity cancer.

**What you can do to lower the risk of a second cancer**

*Quit smoking*

Many of these cancers are linked to tobacco use. In fact, lung cancer, a cancer strongly linked to smoking tobacco, is the most common second cancer in those with a history of mouth or throat cancer.

While it’s not easy to do, quitting tobacco can decrease your risk of many health problems, including another cancer. People who quit smoking have a lower risk of lung, esophagus, larynx, hypopharynx, and oral cavity and oropharynx than those who continue to smoke. See [Stay Away from Tobacco](#) to learn more about quitting tobacco.

*Follow-up after treatment*

After completing treatment for cancer of the oral cavity or oropharynx, you should still see your doctor regularly. Your doctor may order tests to look for signs that the cancer has come back or spread. These tests are also useful in finding some second cancers, particularly a new lung cancer or cancer in the mouth or throat. Experts don’t recommend any other tests to look for second cancers in people who don’t have symptoms. Let your doctor know about any changes or problems you notice, because they could be caused by the cancer coming back or by a new disease or second cancer.

Survivors of oral cavity and oropharyngeal cancers should follow the [American Cancer Society guidelines for the early detection of cancer](#).

To maintain good health, survivors should also:

- Get to and stay at a [healthy weight](#)
- Keep [physically active](#) and limit the time you spend sitting or lying down
- Follow a [healthy eating pattern](#) that includes plenty of fruits, vegetables, and whole grains, and limits or avoids red and processed meats, sugary drinks, and highly processed foods
- Not drink [alcohol](#). If you drink, have no more than 1 drink a day for women or 2 a day for men
These steps can also lower the risk of some other health problems as well as other cancers.

See [Second Cancers in Adults](#) to learn more about the causes of second cancers.

**Hyperlinks**

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