After Treatment

Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- What Happens After Treatment for Oral Cavity and Oropharyngeal Cancers?
- Lifestyle Changes After Having Oral Cavity and Oropharyngeal Cancer
- How Does Having Oral Cavity or Oropharyngeal Cancer Affect Your Emotional Health?

Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about cancer coming back or treatment no longer working.

- Can I Get Another Cancer After Having Oral Cavity or Oropharyngeal Cancer?
- If Treatment for Oral Cavity and Oropharyngeal Cancers Stops Working

What Happens After Treatment for Oral Cavity and Oropharyngeal Cancers?

For some people with oral cavity or oropharyngeal cancer, treatment may remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer growing or coming back. (When cancer comes back after treatment, it is called recurrence.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to live with this uncertainty and are leading full lives. Our
document Living With Uncertainty: The Fear of Cancer Recurrence gives more detailed information on this.

For other people, the cancer may never go away completely. These people may get regular treatments with chemotherapy, radiation therapy, or other therapies to help keep the cancer in check for as long as possible. Learning to live with cancer as more of a chronic disease can be difficult and very stressful. It has its own type of uncertainty. Our document Managing Cancer as a Chronic Illness talks more about this.

**Follow-up care**

After you have completed treatment, your doctors will still want to watch you closely. It is very important to go to all of your follow-up appointments. During these visits, your doctors will ask questions about any problems you are having and will examine you. Your doctor may also order lab tests or imaging tests (such as MRI or CT scans) to look for signs of cancer return. Your health care team will discuss which tests should be done and how often based on the type and initial stage of your cancer, the type of treatment you received, and the response to that treatment.

Patients with cancer of the oral cavity or oropharynx may develop recurrences or new cancers in the head and neck area or lungs. Therefore, they must be followed closely after treatment. Recurrences happen most often in the first 2 years after treatment, so patients are usually examined about every few months during the first 2 years and then less often after that.

For someone who was treated with radiation to the neck, blood tests to look at thyroid function may be needed as well.

With improvements in surgery and radiation therapy, the ability to control a patient’s main cancer has greatly improved. However, development of second cancers in the head and neck or lungs remains an important risk.

Many studies have found that the patient’s quality of life tends to get worse in the first few months after treatment. After that, however, if the patient has given up smoking and drinking alcohol, things tend to get better. Within a year, many patients are feeling reasonably well and happy.

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. Don’t hesitate to tell your cancer care team about any symptoms or side effects that bother you so they can help you manage them.
It is very important to report any new symptoms to the doctor right away, because they may prompt your doctor to do tests that could help find recurrent cancer as early as possible, when the likelihood of successful treatment is greatest.

It’s 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.

If cancer does recur, treatment will depend on the location of the cancer and what treatments you’ve had before. For more information on how recurrent cancer is treated, see the section Treatment Options for Oral Cavity and Oropharyngeal Cancer by Stage. For more general information on dealing with a recurrence, you may also want to see the document Coping With Cancer Recurrence.

**Problems with eating and nutrition**

Cancers of the mouth and throat and their treatments can sometimes cause problems such as trouble swallowing, 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 may need to adjust what they eat during and after treatment. Some may even need a feeding tube placed into the stomach, at least for a short time during and after treatment. You may want to consult with a nutritionist to help find ways to meet your individual nutritional needs. If a dry mouth is making it hard to eat, your doctor may recommend a saliva substitute. This can help you maintain your weight and nutritional intake.

**Speech and swallowing therapy**

Oral cavity or oropharyngeal cancers and their treatments may affect a person’s speech and ability to swallow. A speech therapist may help with these. These experts are knowledgeable about speech and swallowing problems.

**Seeing a new doctor**

At some point after your cancer diagnosis and treatment, you may find yourself seeing a new doctor who does not know anything about your medical history. It is important that you be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at
some point in the future. Make sure you have this information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- If you had surgery, a copy of your operative report
- If you stayed in the hospital, a copy of the discharge summary that doctors prepare when patients are sent home
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored on a CD or DVD.
- If you were treated with radiation, a copy of the treatment
- If you had chemotherapy (or targeted therapy), a list of the drugs, drug doses, and when you took them

The doctor may want copies of this information for his records, but always keep copies for yourself.

- References
  See all references for Oral Cavity and Oropharyngeal Cancers

Can I Get Another Cancer After Having Oral Cavity or Oropharyngeal Cancer?

Cancer survivors can be affected by a number of health problems, but often their greatest concern is facing cancer again. If a cancer comes back after treatment it is called a “recurrence.” But some cancer survivors may develop a new, unrelated cancer later. This is called a “second cancer.” No matter what type of cancer you have had, it is still possible to get another (new) cancer, even after surviving the first.

Unfortunately, being treated for cancer doesn’t mean you can’t get another cancer. People who have had cancer can still get the same types of cancers that other people get. In fact, certain types of cancer and cancer treatments can be linked to a higher risk of certain second cancers.
Patients who have had cancers of the oropharynx can get any type of second cancer, but they have an increased risk of:

- Lung cancer
- Esophagus cancer
- Cancers of the larynx and hypopharynx
- 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
- Cancer of the bile ducts
- Anal cancer
- Cancer of the cervix
- Colon cancer
- Rectal cancer
- Stomach cancer
- Chronic myeloid leukemia
- Hodgkin lymphoma
- Thyroid cancer

Many of these cancers are linked to smoking, and smokers who quit have a lower risk of lung, esophagus, larynx, hypopharynx, and oral cavity and oropharynx than those who continue to smoke.

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

- Lung cancer
- Esophagus cancer
- Cancers of the larynx and hypopharynx
- Another cancer of the oral cavity (this is different than the first cancer coming back)
- Cancer of the oropharynx
- Stomach cancer
- Liver cancer
- Colon cancer
- Rectal cancer
- Cancer of the cervix

Many of these cancers are linked to smoking, and smokers who quit have a lower risk of lung, esophagus, larynx, hypopharynx, and oral cavity and oropharynx than those who continue to smoke.
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 of the mouth or throat. Experts don’t recommend any other tests to look for second cancers in patients who don’t have symptoms. Let your doctor know about any new symptoms or problems, 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 and stay away from tobacco products. Smoking increases the risk of getting certain second cancers as well as other health problems.

To help maintain good health, survivors should also:

- Achieve and maintain a healthy weight
- Adopt a physically active lifestyle
- Consume a healthy diet, with an emphasis on plant foods
- Limit consumption of alcohol to no more than 1 drink per day for women or 2 per day for men

These steps may also lower the risk of some cancers.

See Second Cancers in Adults for more information about causes of second cancers.

- References
See all references for Oral Cavity and Oropharyngeal Cancers

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You can’t change the fact that you have had cancer. What you can change is how you live the rest of your life — making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

**Making healthier choices**

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on the alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society at 1-800-227-2345. A tobacco cessation and coaching service can help increase your chances of quitting for good.

**Eating better**

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. This is especially true for cancers of the head and neck, such as oral cavity or oropharyngeal cancer. The cancer or its treatment may affect how you swallow or cause dry mouth, changes in taste, or other problems. Nausea can be a problem from some treatments. You may not feel like eating and lose weight when you don’t want to.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to manage these treatment side effects.

One of the best things you can do after cancer treatment is put healthy eating habits into place. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.
Rest, fatigue, and exercise

Extreme tiredness, called "fatigue," is very common in people treated for cancer. This is not a normal tiredness, but a “bone-weary” exhaustion that doesn’t get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it is normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. Someone who has never exercised will not be able to take on the same amount of exercise as someone who plays tennis twice a week. If you haven’t exercised in a few years, you will have to start slowly — maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you’re not doing it alone. Having family or friends involved when starting a new exercise program can give you that extra boost of support to keep you going when the push just isn’t there.

If you are very tired, you will need to balance activity with rest. It is OK to rest when you need to. Sometimes it’s really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. (For more information on fatigue and other treatment side effects, please see the Physical Side Effects section of our website.

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.
Can I lower my risk of the cancer progressing or coming back?

Most people want to know if there are specific lifestyle changes they can make to reduce their risk of their cancer progressing or coming back. For many cancers there is little solid evidence to guide people. This doesn’t mean that nothing will help — it’s just that for the most part this is an area that hasn’t been well studied. Most studies have looked at lifestyle changes as ways of preventing cancer in the first place, not slowing it down or preventing it from coming back.

Tobacco and alcohol use have clearly been linked to oral cavity and oropharyngeal cancers, so not smoking or drinking may help reduce your risk of the cancer returning. Smoking during treatment also causes treatment to be less effective, so if you smoke, it is very important to quit. Quitting will reduce your chance of developing other new cancers (especially other head and neck or lung cancers), which is a serious problem among oral cavity and oropharyngeal cancer survivors. Quitting can also help improve your appetite and your overall health. If you want to quit smoking and need help, call the American Cancer Society at 1-800-227-2345.

Adopting other healthy behaviors such as eating well, getting regular physical activity, and maintaining a healthy weight may help as well, 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 cancer.

- References
  See all references for Oral Cavity and Oropharyngeal Cancers

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How Does Having Oral Cavity or Oropharyngeal Cancer Affect Your Emotional Health?

During and after treatment, you may find yourself overcome with many different
emotions. This happens to a lot of people.

You may find yourself thinking about death and dying. Or maybe you’re more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationships with those around you. Unexpected issues may also cause concern. For instance, you may see your health care team less often after treatment and have more time on your hands. These changes can make some people anxious.

Almost everyone who is going through or has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What’s best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It is not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

- References
See all references for Oral Cavity and Oropharyngeal Cancers

If Treatment for Oral Cavity and Oropharyngeal Cancers Stops Working

If cancer keeps growing or comes back after one kind of treatment, it is possible that another treatment plan might still cure the cancer, or at least shrink it enough to help
you live longer and feel better. But when a person has tried many different treatments and the cancer has not gotten any better, the cancer tends to become resistant to all treatment. If this happens, it’s important to weigh the possible limited benefits of a new treatment against the possible downsides. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer – when you have been through many medical treatments and nothing’s working any more. Your doctor may offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. In many cases, your doctor can estimate how likely it is the cancer will respond to treatment you are considering. For instance, the doctor might say that more treatment might have less than a 1 in 100 chance of working. Some people are still tempted to try this. But it is important to think about and understand your reasons for choosing this plan.

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called palliative care.

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose – the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve bone pain caused by cancer that has spread to the bones. Or chemo might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer.

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality of life rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn’t mean you can’t have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more about hospice in our documents called Hospice Care and Nearing the End of Life.
Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends — times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you’ve always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

- References

See all references for Oral Cavity and Oropharyngeal Cancers

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